Ethno-Cultural Differences in Later-Life Caregiving Expectations, Caregiver Burden, Family Dynamics, and Healthcare Decision-Making Factors

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By Mark Lee
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Committee:
Jane M. Onoye, PhD, Mentor
Brett Lu, MD, PhD
Leslie C. Wilson, PhD
Jody Mishan

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Abstract

Keywords: Family Caregiving, Healthcare Decision-Making, Ethno-cultural

Background: In the qualitative literature, Asians and Pacific Islanders (APIs) were generalized to highly value collectivism, suggesting that APIs may have more caregiving responsibilities and obligations, caregiver burden, and group decision-making compared to the general population. **Methods:** A stratified random sample of Euro-American, Japanese, Chinese, and Native Hawaiian children-generation participants (n=106) from the 1970s Hawai‘i Family Study of Cognition cohort was surveyed on measures of family dynamics, caregiver burden, caregiving expectations, actual caregiving responsibilities, importance of healthcare decision-making factors, proximity to parents, communication with parents, and demographics. A subset of survey participants (n=10) was interviewed by phone to provide further context on their families' caregiving and healthcare decision-making. **Results:** APIs were significantly more likely to perceive an expectation to be a family caregiver compared to Euro-Americans. Also, there was a trend for Native Hawaiians being more likely to have actual caregiving and/or decision-making responsibilities compared to Euro-Americans. Qualitative findings, such as a theme for reluctance to use nursing services among APIs, supported these quantitative results. Qualitative analyses provided additional insights into family caregiving and decision-making, including a theme for caregiving duties to be delegated based on circumstantial considerations, and only when caregiving needs arose. **Discussion:** Since some API ethnic groups are more likely to have caregiving expectations and/or caregiving duties, culturally-competent support services for API caregivers may be needed. Qualitative findings also suggest that prevention/intervention strategies for caregiver burden may be helpful for all families, including outreach programs that facilitate long-term planning for later-life healthcare services and caregiving.

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Introduction

Recent demographic trends—including the aging of the Baby Boomer generation and a trend for smaller family sizes—suggest that the demand for informal family caregivers will increase in the future (Redfoot, Feinberg, & Houser, 2013). The demand for family caregivers in the United States (U.S.) is already substantial. The National Alliance for Caregiving and AARP (2015) estimated that 14.3% of Americans provided caregiving to an adult over the age of 50 during the 12-month period before the study. Older populations are at risk for increased morbidity, including a higher rate of Alzheimer's disease and related dementias, which was estimated to affect 13.9% of adults over 71 years of age (Plassman et al., 2007). Seniors living with aging-associated health conditions often require caregiving from family members—e .g., for the three-million Americans with Alzheimer's disease living at home, 75% of their homecare was provided by family and friends (Schulz & Martire, 2004). Between the years of 2010-2030, the number of individuals over the age of 80 was projected to increase by 79%, while the number of individuals between the ages of 45-64 was projected to increase by only 1%; therefore, the population most likely to need long-term services and support (ages 80+) will grow faster, proportionally, than the population most likely to be caregivers (ages 45 to 64) (Redfoot et al., 2013). Using the Level of Care Index to measure caregiver burden, The National Alliance for Caregiving and AARP (2015) estimated that approximately 40% of caregivers were in high burden situations, while 18% were in moderate burden situations. Caregiver burden is especially troublesome for family caregivers of patients with progressive degenerative neurological conditions. It was estimated that 68.0% of caregivers for patients with Alzheimer's type dementia reported a high level of burden and 65% exhibited depressive symptoms (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

The foreboding increase in demand for and strain on family caregivers conveys a need to better understand the role of family members in later-life healthcare decision-making, family dynamics in the healthcare context, and the delegation of caregiving responsibilities. Additional studies in these areas can inform healthcare policy makers and medical professionals on potential strategies for alleviating caregiver strain for informal or unpaid family caregivers.

The United States healthcare system serves a diverse array of ethno-cultural groups, each with their own unique values, beliefs, and traditions. These cultural differences include unique ways of making healthcare decisions, delegating caregiving responsibilities among family members, and structuring the family support network. Research into the ethno-cultural influences on later-life caregiving and decision-making will be important for identifying potential disparities between ethnic groups in the United States and informing the development of culturally-sensitive health policy and healthcare consultations.

Past Studies on Asian and Pacific Islander Values, Beliefs, and Traditions

Asians and Pacific Islanders (APIs) are the fastest growing minority groups, proportionally, in the United States (U.S. Census Bureau, 2010a), which makes them an important population for later-life healthcare research and policy. From 2000 to 2010, the population size of Euro-Americans in the United States increased by 6%, while the population size of Asian Americans (part or mixed) increased by 46% and Pacific Islanders (part or mixed) by 60% (U.S. Census Bureau, 2010a, 2012). APIs are especially important in Hawai‘i due to their large representation compared to the continental United States. According to the American Community Survey in 2013, the proportion of full Asians in Hawai‘i was 37.5%, compared to 5.4% nationally, and the proportion of full Native Hawaiians or Other Pacific Islanders was 10.0% in Hawai‘i, compared to 0.2% nationally (U.S. Census Bureau, 2014c). The focus of this

thesis was to examine the decision-making processes, family dynamics, caregiving responsibility delegation, and caregiver burden of several major API groups in Hawai‘i—Japanese, Chinese, and Native Hawaiians. Japanese and Chinese comprise a large portion of Hawai‘i’s demographic makeup, while Native Hawaiians are an understudied indigenous population. As the predominant majority nationally, as well as having a significant representation in Hawai‘i, Euro-Americans served as the comparison group.

Past Qualitative Studies

McLaughlin and Braun (1998) reviewed several sources, mostly qualitative, to describe the values, beliefs, and traditions of APIs. APIs are typically generalized to have collectivist societies, where decisions are made by families and communities rather than by individuals (Hattori et al., 1991; Hofstede, 1984; Kitano & Kikumura, 1976; Long & Long, 1982; McLaughlin & Braun, 1998). This directly contrasts with the decision-making behaviors of Euro-Americans, who are generalized to be individualistic, and thus, make decisions on their own (McLaughlin & Braun, 1998).

McLaughlin and Braun (1998) also described the beliefs, values, and traditions of several API ethno-racial groups based on the qualitative literature, including the three API groups studied in this thesis. The healthcare behavior of the Japanese is heavily influenced by collective family interests and the preservation of harmony within the family, resulting in the expectation that offspring should happily care for their parents in later life (Hattori et al., 1991; McLaughlin & Braun, 1998). Religious beliefs and customs also play a role in how Japanese interact with healthcare professionals and the healthcare system. Researchers suggested that the Japanese traditionally have two stages in their religious development over the lifespan, where early life is characterized by Shinto beliefs, which emphasizes an avoidance of conversations about death,

and later life is characterized by Buddhist beliefs, which involves the acceptance of death as a part of the cyclical nature of life (Braun & Nichols, 1997; Ikeuchi & Freund, 1995; McLaughlin & Braun, 1998).

The healthcare and caregiving decisions of the Chinese were also said to be predicated on harmony, unity, and family survival (McLaughlin & Braun, 1998). A clear hierarchy is usually established within the family, where responsibilities are delegated to specific family members based on gender, age, and birth order (McLaughlin & Braun, 1998). Respect for senior family members is an important virtue and offspring are often expected to take care of their parents in later life (McLaughlin & Braun, 1998). Also, as demonstrated through the thematic analyses of interviews with 40 Chinese seniors, religious beliefs and values—Confucian, Buddhist, and Taoist—play an important role in later-life healthcare decision-making (Bowman & Singer, 2001). Furthermore, Chinese commonly utilize traditional health remedies as alternatives to western medicine, e.g., acupuncture and herbal medicine (Char, Tseng, Lum, & Hsu, 1980; McLaughlin & Braun, 1998).

Native Hawaiians attribute caring for sick and disabled family members with spiritual significance (Braun, Mokuau, & Tsark, 1997; McLaughlin & Braun, 1998). An example of Native Hawaiian collectivism is the value called *kokua*, which means mutual support and interdependence (Braun et al., 1997; McLaughlin & Braun, 1998). The central tenet of *kokua* is the ability to anticipate the needs of family members, even before it is verbally conveyed (McLaughlin & Braun, 1998). Also, certain aspects of Native Hawaiian cultural practices contrast with western medicine, such as *Lāʻau Lapaʻau* (traditional Hawaiian Medicine), which focuses on holistic healing and wellbeing, compared to allopathic medicine, which historically

was more disease focused (Braun et al., 1997; McLaughlin & Braun, 1998; Stromborg & Olsen, 1993).

Past Quantitative Studies

Several prior studies have quantitatively tested for ethno-racial differences in healthcare decision-making. For example, Frank and colleagues (1998) surveyed European Americans, African Americans, Korean Americans, and Mexican Americans on their attitudes toward end-of-life decision-making. Ethnicity was found to be a significant predictor for attitudes toward patient autonomy—including attitudes toward physician disclosure of information to parents regarding severe/terminal illness, the role of family members in the decision to use life-sustaining technology, and the use of Advance Directives (Frank et al., 1998). A study conducted by Youn, Knight, Jeong, and Benton (1999)**Error! Bookmark not defined.** on Koreans, Korean Americans, and Euro-Americans found that filial piety was most important to Koreans, followed by Korean Americans and then Euro-Americans. Furthermore, Youn and colleagues (1999) observed that Korean and Korean Americans experienced greater levels of caregiver burden and anxiety compared to Euro-Americans. Additional studies on other API ethno-racial groups can help us better understand the generalizability of collectivism to APIs.

The Hawai‘i Family Study of Cognition

The Hawai‘i Family Study of Cognition (HFSC) is a longitudinal study started in the 1970s with 1,818 nuclear families and 6,586 individuals (Onoye et al., 2014). The HFSC cohort is well-suited for ethno-cultural studies because of its rich ethnic composition, including Euro-Americans (53.7%), Japanese Americans (21.0%), Chinese Americans (6.7%), Native Hawaiians (9.9%), and other ethnic groups (8.7%) (Onoye et al., 2014).

In the original 1970s study, nuclear families, which the investigators defined as having "both biological parents, 60 years of age or younger, and one or more of their offspring, 14 years of age or older," served as the sampling units (Wilson et al., 1975). Families were recruited through letter, radio, television announcements, clubs, organizations, and personal referrals by previous participants—with referrals contributing the most to the recruitment rate—and were offered $50 for each family members' participation (Wilson et al., 1975). Although the original HFSC was not longitudinal in design, tracking and tracing of the original participants was reinitiated in 2010 (Onoye et al., 2014). Feasibility studies of longitudinal re-contacting and re-testing of the original HFSC cohort had since been undertaken with the assistance of modern communications and tracking technology, thereby demonstrating the potential viability of the long-term follow up of the HFSC cohort (Onoye et al., 2014).

The current ages of the original children-generation participants (in their 50s) and parent-generation participants (in their 80s) presented an opportunity to assess the decision-making and caregiving relationships between seniors and their offspring.

Purpose and Research Questions

Given the generalizations of API collectivism, APIs in Hawai‘i may have disproportionately greater caregiving expectations and actual caregiving/decision-making responsibilities compared to individualistic ethno-racial groups, such as Euro-Americans. Greater amounts of caregiving duties suggest disproportionately greater caregiver burden for APIs, which may include financial, social, and/or physical strains. Furthermore, the unique spiritual and cultural characteristics of API ethno-racial groups suggest that APIs consider different factors when making healthcare decisions. Lastly, APIs are expected to have better family dynamics compared to Euro-Americans. To test the representativeness of these

hypotheses for APIs in Hawai‘i, a quantitative approach was used to examine ethno-racial differences in a survey sample of Chinese, Japanese, Native Hawaiians, and Euro-Americans from the HFSC longitudinal cohort. To help provide potential explanations for the differences identified in the quantitative analyses, a subset of survey participants were interviewed on their families' caregiving activities, healthcare decision-making, and cultural identifications. Also, because of the complexity of caregiving and healthcare decision-making, the subsequent qualitative approach was selected to provide insights into the context and nuances of these topics. Despite the non-generalizable nature of qualitative results, a mixed quantitative-qualitative approach was valuable because of its ability to statistically test for differences between ethno-racial groups, while providing perspectives in caregiving and decision-making that cannot be elucidated through quantitative methods alone. Thus, the study was designed to answer the following research questions:

Quantitative:

Question 1:	How do Euro-Americans, Japanese, Chinese, and Native Hawaiians differ in terms of prevalence of perceived expectation to be a family caregiver, severity of perceived caregiver burden, prevalence of actual caregiving/decision-making responsibilities, quality of family dynamics, geographic proximity to parents, and frequency of communication with parents?
Question 2:	What are the differences between Euro-Americans, Japanese, Chinese, and Native Hawaiians in the outcome variables listed in Question 1 after controlling for measures of demographics, socioeconomic status, and parents' health conditions.
Question 3:	How do APIs and Euro-Americans differ in terms of factors considered during a recent healthcare decision for their parents?

Qualitative

Question 4: What themes support the quantitative findings that API ethno-racial groups were more likely than Euro-Americans to have an expectation to be a family caregiver, have actual caregiving/decision-making responsibilities, and have more cohesive families?

Methods

The data used for this thesis was collected in two phases. Between August 2014 and May 2015, children-generation participants from the original HFSC cohort were contacted to complete self-administered surveys. Subsequently, between June 2015 and May 2016, structured interviews were conducted with a select group of survey participants. All procedures were approved by the University of Hawai‘i at Mānoa Institutional Review Board. The sampling methodology, measures, and analyses were described separately for the quantitative and qualitative components of this study.

Quantitative Study

Sampling Methodology

The sampling methodology for the survey component of this study is outlined in Figure 1. The original HFSC cohort served as the sampling population. Using an updated participant tracking database, potential subjects were screened according to the following selection criteria: (1) both parents in a family must be currently alive or passed away within the past 18 months; (2) potential participants must be part of the original HFSC “offspring” generation; and (3) potential participants must not have requested to be removed from the mailing list during prior phases.

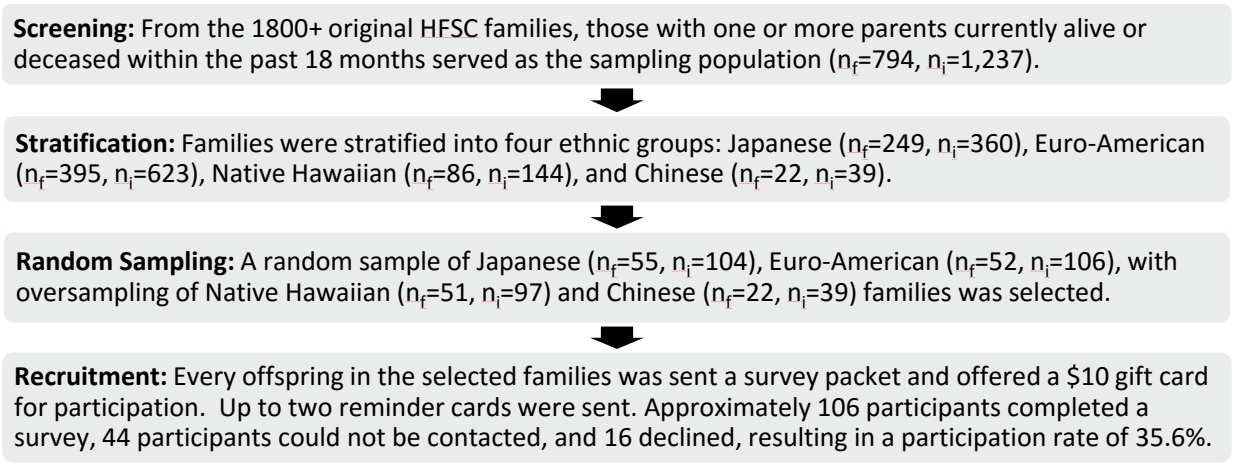

Figure 1. Summary of sampling methodology for the survey component of the study

After inclusion and exclusion criteria were applied, 794 families and 1,237 individuals were left in the sampling population (11.6% Native Hawaiian, 2.3% Filipino, 29.1% Japanese, 3.2% Chinese, 50.4% Euro-American, and 3.5% Korean). The remaining families were then stratified into four ethno-racial groups—Euro-American, Chinese, Native Hawaiian, and Japanese. A simple random sample of families was selected from each of the four ethno-racial groups. Two Chinese families were excluded from the recruitment because of insufficient contact information. Native Hawaiian and Chinese families were oversampled relative to their respective proportions in the original cohort.

All offspring generation members within the selected families were contacted to take part in the study. Participants' contact information was updated using publicly available sources on the internet (e.g., White Pages Pro). Each of the potential participants were then mailed a packet containing: (1) a cover letter thanking them for past HFSC participation, explaining the new study, and inviting them to participate, (2) a survey form (see Appendix A), (3) an informed consent form, (4) a decline card to decline participation and/or remove themselves from the

mailing list, and (5) two pre-stamped and pre-addressed return envelopes. Incentives of $10 gift cards to a retailer were offered. To improve response rates, two reminder cards were sent two weeks and five weeks after the initial mail-out date. Of the randomly selected families, 50 Euro-American families ($n_{individuals}$ = 95), 51 Japanese families ($n_{individuals}$ = 98), 17 Chinese families ($n_{individuals}$ = 30), and 41 Native Hawaiian families ($n_{individuals}$ = 75) were able to be contacted (i.e., no returned mail). A total of 106 individuals and 77 families responded to the survey, yielding a participant response rate of 35.6%.

Measures

The survey (see Appendix A) consisted of five sections, which asked participants to report information about themselves and their parents. Surveys were self-administered and estimated to take 20-30 minutes to complete. The five sections were: (1) participants' and parents' demographics, (2) parents' health status and healthcare utilization, (3) family dynamics and participants' caregiving expectation, (4) participants' caregiver burden, and (5) factors for a recent healthcare decision made by a parent. See Appendix C for detailed descriptions of each variable used in the analyses.

Demographics: Participants provided the following demographic information: participants' gender, age, marital status, ethno-racial identification, history in the military, veteran status, socioeconomic information (current employment status, occupational title, highest educational degree, and relative income), and parents' history in the military. Race/ethnicity was reported in two ways: (1) as a complete listing of all ethno-racial groups that a participant identified with and (2) the ethno-racial group that a participant primarily identified with. The latter was used for ethno-racial comparisons. Income was reported as a categorical variable relative to an individual median annual income of $39,000.

Parents' Health Status and Healthcare Utilization: Participants were asked to report on their parents' healthcare utilization. If a parent was deceased, participants were asked to report their parents' healthcare utilization during the time before their parents' passing. If participants had no recollection of their parents' healthcare utilization for a stated time period, they were asked to report that they did not know the details. Participants were then asked to report their parents' mental and physical health conditions using Question Two from the Activity Limitations Module of the Center for Disease Control and Prevention's (CDC) Health Related Quality of Life (HRQOL) Healthy Days Measure (Center for Disease Control and Prevention, 2011). An option for "Dementia" was added to the question to identify parents with progressive degenerative neurological conditions. Parents' health complications were categorized by type: mobility, audiovisual sensory, cardiovascular/respiratory, and mental health.

The participants were then asked about the utilization of specific healthcare services by their parents, including: (1) visits to a healthcare professional other than a routine checkup within the past month, (2) use of a nursing home/facility or nursing help/assistance in the home, (3) number of nights stayed in the hospital in the past year, (4) number of visits to the emergency room in the past year, and (5) use of surgical services in the past year. To provide a financial context for the parents' healthcare utilization, the types of resources used to pay for healthcare services were reported by the participants. For the analyses, participants were coded as either having parents that use government insurance (Medicare or Medicaid) or not.

Caregiving Expectation and Family Dynamics: Participants were also asked to report if they perceived an expectation to be a caregiver for their mother and father, their geographical proximity to their parents, their frequency of communication with their parents, and to complete the Family APGAR—Adaption, Partnership, Growth, Affection, Resolve (Smilkstein, 1978).

Expectation for caregiving was assessed in two ways: expectation for caregiving in general and expectation for caregiving specifically due to a cultural reason. The Family APGAR is a subjective scale that measures "the satisfaction of an individual with each of the five basic components of family function" (Smilkstein, 1978). The scores for each of the five components of family function were summed to create a composite score that rates overall family dynamics, where 7-10 implies "a highly functional family," 4-6 "a moderately dysfunctional family," and 0-3 "a severely dysfunctional family" (Smilkstein, 1978). To make the Family APGAR more pertinent to the healthcare context, the questions were modified to reflect dynamics during a time of health concern or crisis.

A study by Gardner et al. (2001) used a sample of office-based visits (N=21,285) to assess the internal consistency of the Family APGAR. The Cronbach's alpha analyses resulted in a coefficient α=0.85, indicating that the five items in the Family APGAR measured the same underlying factor (Gardner et al., 2001). A Cronbach's alpha analyses using the sample for this honors thesis yielded an α=0.852, supporting the conclusion that the Family APGAR is internally consistent. Limitations to the Family APGAR, howevever, were reported by Gardner et al. (2001), including the temporal inconsistency of Family APGAR scores over two points in time and the lack of agreement of Family APGAR scores with physician assessments.

Caregiver Burden: Participants were asked to self-report their participation in caregiving/decision-making (in the past or currently) and their perceived caregiver burden. The 10-item short version of the Burden Scale for Family Caregivers (BSFC-s) was used to measure participants' perceived caregiver burden. Each of the 10 items had five choices: strongly disagree, disagree, neutral, agree, and strongly agree, which were scored as 0, 1, 1.5, 2, and 3, respectively. The scale is a subjective set of 10 items that measures five aspects of coping and

social support (Graessel, Berth, Lichte, & Grau, 2014). These five theoretical components include: (1) background and context, (2) primary stressors, (3) secondary role strains, (4) secondary intrapsychic role strains, and (5) outcomes (Graessel et al., 2014; Pearlin, Mullan, Semple, & Skaff, 1990).

Graessel and colleagues (2014) found that there was a high level of internal consistency within the 10-item scale (α=0.92). Furthermore, BSFC-s scores were significantly correlated with measures of severity of cognitive impairments of the care-receivers, disturbing behavior of the care-receivers, mental health of caregivers, involvement with the care-recievers, and demand of care. A Cronbach's alpha calculation using this honors thesis sample produced an α=0.948.

Healthcare Decision-Making Factors: Participants were asked to report on a recent healthcare decision made by a parent and the factors that were considered during the decision-making process. The participants were asked to briefly describe the healthcare decision to provide a context. Participants were then asked to score the importance (not important, moderately important, or very important) of ten decision-making factors for their parents' recent healthcare decision: (1) financial resources and cost of healthcare, (2) healthcare professional recommendations, (3) risks of procedure, (4) burden on family, (5) opinions and preferences of family members, (6) cultural traditions/values or alternative healing practices, (7) trust in the healthcare team or system, (8) availability of healthcare, (9) seeking or availability of information, and (10) personal wishes of parents.

Data Analyses

Using SAS 9.2, generalized linear mixed models (proc GLIMMIX procedure) and general linear mixed models (proc MIXED procedure) were used to assess the ethnic differences for the categorical and continuous response variables, respectively. For each of the procedures,

an unadjusted and adjusted model was analyzed. The unadjusted models had primary ethnic identification as the explanatory variable and families as the random factor. Along with the two variables of primary ethnic identification and families, the adjusted models included measures of demographics, socioeconomic status, and parents' health as explanatory variables, to serve as controls. The Kenward-Rodger degrees of freedom approximation was used in these analyses, except when the importance of decision-making factors was the response variable, for which the Containment approximation was used instead. The models are summarized in Tables 1 and 2. The assumptions for each model were assessed to ensure the validity of the results (see Appendix D). Each of the continuous response variables were assessed for a normal distribution of the residuals. Since the residual plots for the Family APGAR regression models had a long-left tail, the scores were cubed to make the distributions more symmetric. Prior publications discussed the increased power of the general linear models procedure that results from transforming skewed data (Levine & Dunlap, 1982).

Table 1: Summary of variables used in the generalized linear mixed models

Generalized Linear Mixed Models	
Unadjusted	**Adjusted**
Response variables (each of the following response variables were modeled separately): • Expectation to be a caregiver for mother • Expectation to be a caregiver for father • Expectation to be a caregiver for a cultural reason • Actual caregiving/decision-making responsibility for mother • Actual caregiving/decision-making responsibility for father • Geographic proximity to mother • Geographic proximity to father • Frequency of communication with mother • Frequency of communication with father ***Explanatory variable:*** • Participants' primary ethnic identification ***Random Factor:*** • Families	***Response variables*** (each of the following response variables were modeled separately): • Expectation to be a caregiver for mother • Expectation to be a caregiver for father • Expectation to be a caregiver for a cultural reason • Actual caregiving/decision-making responsibility for mother • Actual caregiving/decision-making responsibility for father • Geographic proximity to mother • Geographic proximity to father • Frequency of communication with mother • Frequency of communication with father ***Explanatory variable:*** • Participants' primary ethnic identification • Participants' gender • Participants' annual income • Participants' highest educational attainment • Parents' military history • Parents' emergency room utilization (mother, father, or combined depending on response variable) • Parents' government insurance utilization (mother, father, or combined) • Presence of a mental health condition in parent (mother, father, or combined) ***Random Factor:*** • Families

Table 2: Summary of variables used in general linear mixed models

General Linear Mixed Models	
Unadjusted	**Adjusted**
Response variables (each of the following response variables were modeled separately): • Cubed Family APGAR scores • BSFC-s scores ***Explanatory variable:*** • Participants' primary ethnic identification ***Random Factor:*** • Families	***Response variables*** (each of the following response variables were modeled separately): • Cubed family APGAR scores • BSFC-s scores ***Explanatory variable:*** • Participants' primary ethnic identification • Participants' gender • Participants' annual income • Participants' highest educational attainment • Parents' military history • Parents' emergency room utilization (mother, father, or combined depending on response variable) • Parents' government insurance utilization (mother, father, or combined) • Presence of a mental health condition in parent (mother, father, or combined) ***Random Factor:*** • Families

As suggested by the qualitative literature on API collectivism, a priori expectations for API participants include: (1) higher prevalence of expectation to be a caregiver for parents, (2) greater caregiver burden, (3) better family dynamics, (4) higher prevalence of actual caregiving/decision-making responsibilities, (5) higher frequency of communication with parents, and (6) closer geographic proximity to parents, compared to Euro-Americans. To test these hypotheses, one pre-planned contrast and three multiple comparisons were used for each regression model, as summarized in Table 3. The proc GLIMMIX and proc MIXED procedures were used to conduct t-tests for these pre-planned contrasts and multiple comparisons. All t-values reported were based on the differences between Euro-Americans and APIs for averages of scores (for continuous response variables) or averages of proportions (for categorical response

variables). All p-values were based on one-sided tests, with the exception of hypothesis tests for the importance of healthcare decision-making factors, which were two sided.

Table 3: Summary of null hypotheses and alternative hypotheses for pre-planned contrasts and multiple comparisons

Test	Null Hypothesis	Alternative Hypothesis
Pre-planned contrast	$\frac{\mu_{CH} + \mu_{JA} + \mu_{NH}}{3} = \mu_{EA}$	$\frac{\mu_{CH} + \mu_{JA} + \mu_{NH}}{3} > \mu_{EA}$
Multiple Comparison 1	$\mu_{CH} = \mu_{EA}$	$\mu_{CH} > \mu_{EA}$
Multiple Comparison 2	$\mu_{JA} = \mu_{EA}$	$\mu_{JA} > \mu_{EA}$
Multiple Comparison 3	$\mu_{NH} = \mu_{EA}$	$\mu_{NH} > \mu_{EA}$

CH = Chinese, JA = Japanese, NH = Native Hawaiian, and EA = Euro-American

Qualitative Study

Sampling Methodology

The sampling methodology for the interview component of this study is summarized in Figure 2. Of the 106 survey participants, 33 were re-contacted to take part in follow-up structured interviews (see Appendix B for the interview form). To be selected for re-contact, participants had to meet the following selection criteria: (1) participant had an expectation to be a caregiver for at least one parent and (2) participant had a caregiving/decision-making responsibility for a parent. The re-contact group consisted of 3 Chinese families (3 individuals), 10 Japanese families (11 individuals), 9 Native Hawaiian families (10 individuals), and 7 Euro-American families (9 individuals). All participants meeting the selection criteria were sent a recruitment packet, which included a cover letter, consent form, decline card, and pre-stamped and pre-addressed return envelope. As described in the consent form and cover letter, participants were offered a $20 gift card to a retailer for participating in a structured telephone interview. If participants were interested in being interviewed, they were asked to complete and return the enclosed consent form and call the HFSC office to schedule an interview. Participants

were mailed two reminder cards four and five weeks after the original mailing date. Only one participant was not able to be reached due to inaccurate mailing information. Out of the re-contacted participants, a total of 9 families and 10 individuals participated in the interviews, yielding a participant response rate of 30.3%.

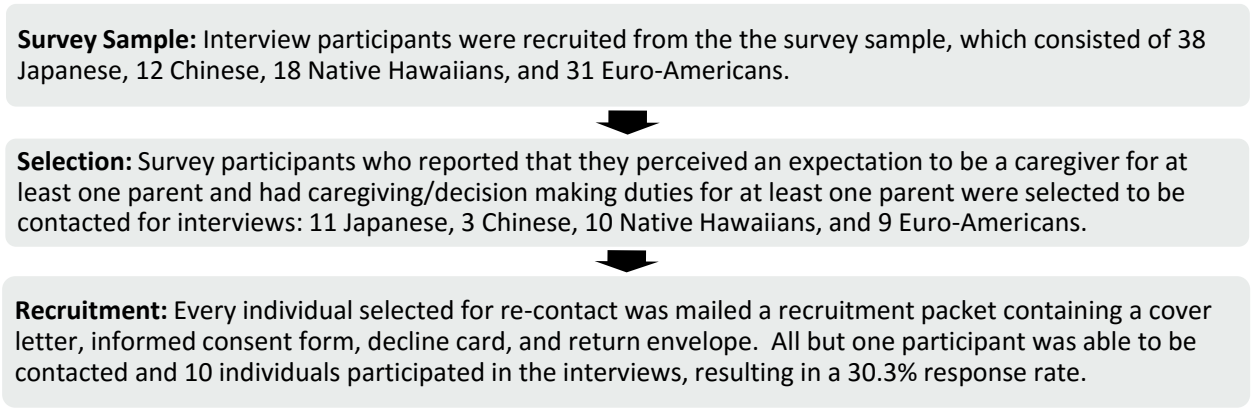

Figure 2. Summary of sampling methodology for the interview component of the study

Measures

Structured interviews were conducted over the phone and ranged from 25-60 minutes in duration, with most interviews taking approximately 40 minutes to complete. The participants' responses were documented in an electronic file (see Appendix B) by the interviewer as the interview was being conducted. Although the participants' responses were not recorded and transcribed verbatim, the interview transcripts maintained the substantive content, chronological order, and the approximate length for which topics were discussed by the participants.

A modified version of the qualitative Family APGAR was used to further assess the social support networks for the participants' elderly parents. The qualitative Family APGAR consisted of five questions, including how the participant (1) worked with his/her siblings,

friends, and community to assist his/her parents during a healthcare concern or crisis, (2) communicated with family members about his/her parents' medical care, (3) helped support the development of independent lifestyles for his/her parents, (4) supported his/her parents emotionally, and (5) shared resources (time, space, and money) with his/her parents.

Participants were also asked to describe the cues that led them to believe that they had an expectation to provide caregiving for their parents. Subsequently, participants reported how caregiving responsibilities were delegated among family members. To assess families' level of preparation for later-life healthcare and caregiving, participants were asked to describe how prepared they felt in providing caregiving and how their families prepared financially for later-life healthcare services.

To better understand the participants' affiliation with their heritage culture, they were asked to discuss how strongly they identified with the culture of their primary ethno-racial identification compared to either the API or Euro-American culture. Also, participants were asked to discuss their and their parents' attitudes toward traditional and alternative medicine.

Participants were then asked to describe the entire decision-making process for a recent healthcare decision for their parents and how well healthcare providers communicated with them during this process. Lastly, participants discussed their strategies for coping with the financial, physical, and emotional stresses of caregiving and the fulfillment they experienced as a family caregiver.

Data Analyses

The qualitative responses to the interview questions were analyzed using interrater agreement. One researcher coded and identified themes for all 10 interviews, while two

researchers independently coded and identified themes for 5 interviews each. The 15 interview questions were partitioned into 6 different topics, as summarized in Table 4. A priori themes for each of the six topics were created based on cultural theories on API healthcare decision-making and caregiving from McLaughlin and Braun's (1998) review article. The themes were created for Euro-Americans and APIs separately, to reflect the theorized differences between the two groups in the literature, however, during coding, individuals' responses could be coded for both "Euro-American" and "API" themes. This coding strategy allowed us to assess the representativeness of the theorized a priori themes for APIs and Euro-Americans in Hawai‘i.

Table 4: Summary of topics for the qualitative analysis and a priori themes

Social Support Network (Questions 1 through 10)	
Euro-American	Asians and Pacific Islander
• Daily activities handled by parents or formal caregivers • Parental preparation for later-life healthcare and retirement • Family open to nursing home care • Concern with independence for parents • Family open to discuss death, dying, and later-life plans	• Caregiving duties handled by offspring • Offspring prepared in advance for parents' later-life healthcare and retirement • Family reluctant to use nursing home services • Silent communication of caregiving expectation through cultural norms • Concern with preservation of harmony within the family • Family reluctant to discuss death, dying, and later-life plans
Identification with Heritage Culture (Questions 11 and 12)	
Euro-American	Asians and Pacific Islander
• Values western individualism • Participant distrusts/does not use alternative medicine • Family member distrusts/does not use alternative medicine	• Values API collectivism • Affiliates with API practices, customs, and people • Participant trusts/uses alternative medicine • Family member trusts/uses alternative medicine
Healthcare Decision-Making (Question 13)	
Euro-American	Asians and Pacific Islander
• Parental determination in healthcare decision • Disparity in information between parents and family members • Open to questioning healthcare authority figures • Open to discussions of death and dying	• Soliciting opinions from offspring • Deferring decision-making to specific offspring • All family members having equal information • Concern for preservation of harmony within the family • Complete trust in healthcare authority figures • Reluctance to discuss death and dying
Acquisition of Information from Health Professionals (Question 14)	
Euro-Americans	Asians and Pacific Islanders
No a priori themes	No a priori themes
Coping Strategies (Question 15 Part 1)	
Euro-Americans	Asians and Pacific Islanders
No a priori themes	No a priori themes
Fulfillment from Caregiving (Question 15 Part 2)	
Euro-Americans	Asians and Pacific Islanders
No a priori themes	• Deep gratitude and happiness for caregiving responsibilities • Spiritual significance in caregiving

The researchers followed an iterative process for coding the transcripts and identifying themes in the responses. The researchers worked on one of the six topics at a time. For each topic, the researchers started by reading each participant's interview to identify portions of the responses that belonged to the first a priori theme. During this initial coding of the participant

responses, any new themes observed were identified for coding in a subsequent coding iteration. If a topic did not contain any a priori themes, then the initial read-through was used to identify new themes in the interview responses. The researchers repeated this process for each of the remaining a priori and newly identified themes. Upon completion of the coding by all three independent researchers, the coded themes were compared and discussed until agreement was reached for the final themes and coding. After all three researchers were in agreement, one researcher reviewed all of the themes and categorized them into overarching themes. The researchers were sensitized to the topics being assessed through reading of the literature, personal experiences, and discussions within the team.

Results

Quantitative Study

Sample Description

A total of 31 Euro-Americans (31.3%), 12 Chinese (12.1%), 38 Japanese (38.4%), and 18 Native Hawaiians (18.2%) completed the survey. The survey sample was comprised of a greater proportion of females (57.6%) compared to males (42.4%). Participants were between 51 and 68 years of age, with the average age being 55.8 years (sd: 2.79 years). There was an overrepresentation of military families in the sample, with approximately 52.6% of participants having a parent who was in the military. Participants typically were of relatively higher socioeconomic status (78.8% earning over $39,000 per year) and well-educated (74.4% having earned a bachelor's degree or higher). As a result of the advanced age of the parent generation, there was a high incidence of mental health complications (37.4% of participants having at least one parent with depression, anxiety, emotional problems, and/or dementia) and healthcare utilization (45.8% of participants having at least one parent visit the emergency room within the

past year). Tables 5 and 6 summarize the descriptive statistics of the control variables used in the multiple regression models by primary ethnic identification. There were no significant ethnic differences for the control variables in the model. Chi-square analyses having less than 5 observations in a cell should be interpreted with caution.

Table 5: Association between primary ethnic identification and categorical explanatory variables

	Euro-American			**Chinese**			**Japanese**			**Native Hawaiian**			**Comparison**		
	Freq.	***N***	***%***	***Freq.***	***N***	***%***	***Freq.***	***N***	***%***	***Freq.***	***N***	***%***	χ^2	***df***	***p***
Participants' gender															
Male	9	31	29.0	4	12	33.3	21	38	55.3	8	18	44.4	5.28	3	0.153
Female	22	31	71.0	8	12	66.7	17	38	44.7	10	18	55.6			
Parent previously in military?															
Yes	17	30	56.7	3	12	25.0	20	38	52.6	11	17	64.7	4.86	3	0.182
No	13	30	43.3	9	12	75.0	18	38	47.4	6	17	35.3			
Participants' highest level of education															
2-year degree or below	10	31	32.3	1	12	8.3	7	38	18.4	7	18	38.9	7.02	6	0.319
Bachelor's degree	13	31	41.9	7	12	58.3	15	38	39.5	5	18	27.8			
Graduate or professional degree	8	31	25.8	4	12	33.3	16	38	42.1	6	18	33.3			
Participants' annual income															
At or below $39,000	9	31	29.0	1	12	8.3	6	38	15.8	5	18	27.8	3.46	3	0.326
Above $39,000	22	31	71.0	11	12	91.7	32	38	84.2	13	18	72.2			
Mother visited emergency room in the past year															
Yes	5	29	17.2	4	12	33.3	9	33	27.3	8	16	50.0	5.54	3	0.136
No	24	29	82.8	8	12	66.7	24	33	72.7	8	16	50.0			
Father visited emergency room in the past year															
Yes	12	24	50.0	2	11	18.2	8	27	29.6	4	12	33.3	4.09	3	0.252
No	12	24	50.0	9	11	81.8	19	27	70.4	8	12	66.7			
One or both parents visited emergency room in the past year															
Yes	13	30	43.3	4	12	33.3	16	37	43.2	11	17	64.7	3.37	3	0.338
No	17	30	56.7	8	12	66.7	21	37	56.8	6	17	35.3			
Mother uses Medicare and/or Medicaid															
Yes	24	31	77.4	8	12	66.7	31	38	81.6	14	18	77.8	1.18	3	0.758
No	7	31	22.6	4	12	33.3	7	38	18.4	4	18	22.2			
Father uses Medicare and/or Medicaid															
Yes	19	31	61.3	8	12	66.7	18	38	47.4	7	18	38.9	3.67	3	0.300
No	12	31	38.7	4	12	33.3	20	38	52.6	11	18	61.1			
One or both parents uses Medicare and/or Medicaid															
Yes	24	31	77.4	9	12	75.0	33	38	86.8	14	18	77.8	1.49	3	0.685
No	7	31	22.6	3	12	25.0	5	38	13.2	4	18	22.2			
Mother has a mental health problem															
Yes	7	31	22.6	2	12	16.7	6	38	15.8	6	18	33.3	2.43	3	0.487
No	24	31	77.4	10	12	83.3	32	38	84.2	12	18	66.7			
Father has a mental health problem															
Yes	9	31	29.0	4	12	33.3	8	38	21.1	4	18	22.2	1.09	3	0.779
No	22	31	71.0	8	12	66.7	30	38	78.9	14	18	77.8			
One or both parents have a mental health problem															
Yes	11	31	35.5	6	12	50.0	13	38	34.2	7	18	38.9	1.05	3	0.790
No	20	31	64.5	6	12	50.0	25	38	65.8	11	18	61.1			

Table 6: Association between primary ethnic identification and age

	Euro-American			Chinese			Japanese			Native Hawaiian			Comparison		
	N	***Mean***	***s.d.***	***N***	***Mean***	***s.d.***	***N***	***Mean***	***s.d.***	***N***	***Mean***	***s.d.***	***F***	***df***	***p***
Age	31	54.9	2.4	12	56.9	4.1	36	55.9	2.4	17	56.5	3.0	2.13	3, 92	0.101

Descriptive Statistics for Response Variables

Tables 7 and 8 summarize the descriptive statistics of the response variables by primary ethnic identification. For the combined sample, there was a large proportion of participants who perceived an expectation to be a caregiver for their parents (for mother: 47.9%; for father: 35.7%). A slightly smaller proportion of participants had actual caregiving and/or decision-making responsibilities (for mother: 45.3%; for father: 32.2%). Approximately 28.6% of participants attributed their expectation to be a caregiver to a cultural reason. Exactly half of participants lived within a 30-minute drive from their mothers and 40.3% lived within a 30-minute drive from their fathers. The large majority of participants communicated with their parents at least once a week (with mother: 86.2%; with father: 75.7%).

Table 7: Distribution of categorical response variables by primary ethnic identification

Response variable	Response	Euro-American			Chinese			Japanese			Native Hawaiian		
		Freq.	*N*	*%*	*Freq.*	*N*	*%*	*Freq.*	*N*	*%*	*Freq.*	*N*	*%*
Expectation to provide caregiving for mother	Yes	10	30	33.3	8	12	66.7	17	36	47.2	10	16	62.5
	No	20	30	66.7	4	12	33.3	19	36	52.8	6	16	37.5
Expectation to provide caregiving for father	Yes	6	29	20.7	6	11	54.6	12	31	38.7	6	13	46.2
	No	23	29	79.3	5	11	45.5	19	31	61.3	7	13	53.9
Expectation to provide caregiving for a cultural reason	Yes	6	31	19.4	3	12	25.0	12	38	31.6	7	17	41.2
	No	25	31	80.7	9	12	75.0	26	38	68.4	10	17	58.8
Actual caregiving/decision-making for mother	Yes	12	31	38.7	4	12	33.3	17	36	47.2	10	16	62.5
	No	19	31	61.3	8	12	66.7	19	36	52.8	6	16	37.5
Actual caregiving/decision-making for father	Yes	11	30	36.7	2	12	16.7	13	35	37.1	3	13	23.1
	No	19	30	63.3	10	12	83.3	22	35	62.9	10	13	76.9
Geographic proximity to mother	Within a 30-minute drive away	9	31	29.0	7	12	58.3	22	35	62.9	9	16	56.3
	More than a 30-minute drive away	22	31	71.0	5	12	41.7	13	35	37.1	7	16	43.8
Geographic proximity to father	Within a 30-minute drive away	7	28	25.0	6	11	54.6	14	26	53.9	4	12	33.3
	More than a 30-minute drive away	21	28	75.0	5	11	45.5	12	26	46.2	8	12	66.7
Frequency of communication with mother	At least weekly	29	31	93.6	11	12	91.7	25	35	71.4	16	16	100.0
	At most monthly	2	31	6.5	1	12	8.3	10	35	28.6	0	16	0.0
Frequency of communication with father	At least weekly	25	26	96.2	6	11	54.6	18	26	69.2	7	11	63.6
	At most monthly	1	26	3.9	5	11	45.5	8	26	30.8	4	11	36.4

Table 8: Descriptive statistics for continuous response variables by primary ethnic identification

Response variable	Euro-American			Chinese			Japanese			Native Hawaiian		
	N	*Mean*	*s.d.*	*N*	*Mean*	*s.d.*	*N*	*Mean*	*s.d.*	*N*	*Mean*	*s.d.*
Family APGAR cubed	31	708.7	344.2	12	871.4	257.2	38	723.2	334.2	18	891.2	223.1
BSFC-s	14	8.5	7.9	3	12.0	5.6	20	9.3	6.7	11	10.3	6.0

Ethno-racial Differences in Categorical Response Variables

Results from the unadjusted generalized linear mixed models are summarized in Table 9. Without controlling for measures of demographics, socioeconomics, and parents' health, APIs were significantly more likely to have an expectation to be a caregiver for their mothers and

fathers, compared to Euro-Americans. Specifically, Chinese and Native Hawaiians were more likely to have an expectation to be a caregiver for their parents, compared to Euro-Americans. Although the proportion of Japanese participants who perceived an expectation to provide caregiving for their parents was slightly greater than Euro-Americans, the proportion was smaller than that of Chinese and Native Hawaiians. No significant differences between ethno-racial groups were found for expectation to provide caregiving because of a cultural reason, actual caregiving/decision-making responsibilities, geographic proximity to mother, and frequency of communication with father. However, there was a trend ($p<0.1$) for greater actual caregiving/decision-making responsibilities and expectation for caregiving due to a cultural reason for Native Hawaiians, compared to Euro-Americans. Also, APIs were significantly more likely to live within a 30-minute drive from their fathers.

Table 9: Results from the unadjusted generalized linear mixed models

	Pre-planned contrast			**Multiple comparisons**								
	CH, JA, & NH > EA			**CH > EA**			**JA > EA**			**NH > EA**		
Response variable	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***
Expectation to provide caregiving for mother (n=94)	-2.09	52.1	0.021*	-1.83	39.2	0.038*	-1.07	49.02	0.145	-1.79	70.2	0.039*
Expectation to provide caregiving for father (n=84)	-2.09	54.2	0.021*	-1.89	28.2	0.034*	-1.41	54.9	0.082	-1.58	65.0	0.060
Expectation to provide caregiving for a cultural reason (n=98)	-1.22	80.2	0.114	-0.41	63.3	0.343	-1.10	74.3	0.138	-1.53	82.4	0.065
Actual caregiving/decision-making for mother (n=95)	-0.71	57.6	0.239	0.16	53.3	0.563	-0.52	53.9	0.304	-1.38	74.1	0.085
Actual caregiving/decision-making for father (n=90)	0.98	72.1	0.836	0.99	86.0	0.837	0.18	58.0	0.570	0.82	86.0	0.793
Geographic proximity to mother (n=94)	-2.60	1	0.117	-1.74	1	0.166	-2.69	1	0.113	-1.79	1	0.162
Geographic proximity to father (n=77)	-1.79	35.6	0.041*	-1.64	19.6	0.059	-2.10	33.9	0.022*	-0.53	51.2	0.298
Frequency of communication with mother	Did not converge											
Frequency of communication with father (n=74)	2.47	70	0.992	2.47	70	0.992	2.08	70	0.979	2.13	70	0.982

CH = Chinese, JA = Japanese, NH = Hawaiian, and EA = Euro-American

*$p<0.05$

Results from the adjusted generalized linear mixed models are summarized in Table 10. After controlling for demographic, socioeconomic, and parents' health factors, APIs were still significantly more likely to have an expectation to provide caregiving for both parents, compared to Euro-Americans. Also, Chinese participants were significantly more likely than Euro-Americans to have an expectation to provide caregiving for their mothers, while greater caregiving expectation for their fathers became a trend. There were also trends for greater expectations to provide caregiving for both parents for Japanese and Native Hawaiians, relative to Euro-Americans. Furthermore, there was a trend for greater caregiving expectations because of cultural reasons for APIs. Multiple comparisons showed a trend for greater expectation to provide caregiving because of cultural reasons for Native Hawaiians compared to Euro-Americans. The adjusted model showed no significant differences between ethno-racial groups for geographic proximities to fathers, but APIs were significantly more likely to live closer to their mothers than Euro-Americans.

Table 10: Results from adjusted generalized linear mixed models

Response variable	Pre-planned contrast			Multiple comparisons								
	CH, JA, & NH > EA			CH > EA			JA > EA			NH > EA		
	t	*df*	*p*	*t*	*df*	*p*	*t*	*df*	*p*	*t*	*df*	*p*
Expectation to provide caregiving for mother (n=83)	-2.17	58	0.017*	-1.98	33.8	0.028*	-1.61	44.9	0.057	-1.49	64.3	0.071
Expectation to provide caregiving for father (n=68)	-1.74	55.0	0.043*	-1.51	41.4	0.070	-1.38	55.0	0.086	-1.42	55.0	0.080
Expectation to provide caregiving for a cultural reason (n=91)	-1.40	78.0	0.083	-0.51	62.3	0.304	-1.50	76.1	0.069	-1.51	78.0	0.067
Actual caregiving/decision-making for mother (n=83)	0.67	39.2	0.746	0.31	47.4	0.619	0.75	34.7	0.771	0.55	38.9	0.707
Actual caregiving/decision-making for father (n=69)	0.22	46.8	0.586	-0.52	53.9	0.302	-0.35	43.7	0.365	1.28	56.0	0.898
Geographic proximity to mother (n=85)	-2.10	37.8	0.021*	-1.38	28.9	0.089	-2.68	39.8	0.005*	-1.04	48.2	0.152
Geographic proximity to father (n=65)	-1.07	37.0	0.147	-0.77	30.5	0.223	-2.09	38.7	0.022*	0.17	47.4	0.569
Frequency of communication with mother	Did not converge											
Frequency of communication with father	Did not converge											

CH = Chinese, JA = Japanese, NH = Native Hawaiian, and EA = Euro-American
*$p<0.05$

Ethno-racial Differences in Continuous Response Variables

Tables 11 and 12 summarize findings from the unadjusted and adjusted general linear mixed models, respectively. For the unadjusted model, Native Hawaiians had significantly larger cubed Family APGAR scores compared to Euro-Americans. In the adjusted model, there was a trend ($p<0.1$) for greater cubed Family APGAR scores for Native Hawaiians, relative to Euro-Americans. Although Chinese had a larger average cubed Family APGAR score than Euro-Americans, the size of the Chinese group was small, making for reduced power. Furthermore, although the average BSFC-s scores for each of the API ethno-racial groups were larger than Euro-Americans, no statistically significant differences were found since only 58 participants completed the BSFC-s.

Table 11: Results from the unadjusted general linear mixed models

	Pre-planned contrast			Multiple comparisons								
	CH, JA, & NH > EA			CH > EA			JA > EA			NH > EA		
Response variable	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***
Family APGAR cubed (n=99)	-1.27	64.0	0.104	-1.06	64.4	0.146	0.06	63.6	0.523	-1.79	68.1	0.039*
BSFC-s (n=58)	-0.66	32.8	0.255	-0.67	37.4	0.252	-0.35	28.3	0.364	-0.41	33.1	0.344

CH = Chinese, JA = Japanese, NH = Native Hawaiian, and EA = Euro-American
*$p<0.05$

Table 12: Results from the adjusted general linear mixed models

	Pre-planned contrast			Multiple comparisons								
	CH, JA, & NH > EA			CH > EA			JA > EA			NH > EA		
Response variable	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***	***t***	***df***	***p***
Family APGAR cubed (n=91)	-1.03	57.5	0.154	-1.03	58.7	0.153	0.25	56.6	0.599	-1.37	62.0	0.087
BSFC-s (n=42)	-0.47	28.6	0.320	-0.25	29.0	0.404	-0.46	23.3	0.323	-0.48	27.9	0.319

CH = Chinese, JA = Japanese, NH = Native Hawaiian, and EA = Euro-American
*$p<0.05$

Ethno-racial Differences in Healthcare Decision-Making Factors

The differences by primary ethnic identification for the importance of decision-making factors for a parents' recent healthcare decision are summarized in Table 13. There was a trend ($p<0.1$) for greater importance of "Financial Resources and Cost of Healthcare" in the decision-making process for APIs compared to Euro-Americans. For both Euro-Americans and APIs, "Personal Wishes of the Parent" was the most important healthcare decision-making factor. The majority of Euro-Americans and APIs reported healthcare system and health condition related factors as important (i.e., availability of healthcare, trust in the healthcare system, risk of procedures, and healthcare professional recommendations/expectations). Also, the majority of participants reported that the opinions and preferences of family members were important. About half of the participants reported that burden on family was an important consideration. For both Euro-Americans and APIs, cultural traditions/values and alternative medicine was the

least important decision-making factor; however, a relatively large proportion of participants still considered the factor to be important in the healthcare decision (about 25%).

Table 13: Results from the generalized linear mixed models with importance of healthcare decision-making factors as the response variables

Factor	Response	Euro-American			API			Unadjusted		
		Freq.	*N*	*%*	*Freq.*	*N*	*%*	*F*	*df*	*p*
Financial resources and cost of healthcare	Important	5	19	26.3	20	37	54.1	3.21	1, 12	0.099
	Not important	14	19	73.7	17	37	46.0			
Healthcare professional recommendations or expectations	Important	15	19	79.0	33	35	94.3	2.59	1, 12	0.133
	Not important	4	19	21.1	2	35	5.7			
Risks of procedure	Important	12	18	66.7	26	32	81.3	1.03	1, 10	0.333
	Not important	6	18	33.3	6	32	18.8			
Burden on family	Important	9	19	47.4	20	36	55.6	0.33	1, 12	0.576
	Not important	10	19	52.6	16	36	44.4			
Opinions and preferences of family members	Important	13	19	68.4	24	37	64.9	0.13	1, 12	0.725
	Not important	6	19	31.6	13	37	35.1			
Cultural traditions/values or alternative health practices	Important	3	18	16.7	10	34	29.4	0.99	1, 11	0.340
	Not important	15	18	83.3	24	34	70.6			
Trust in healthcare team or system	Important	19	19	100	30	36	83.3	Did not converge		
	Not important	0	19	0	6	36	16.7			
Availability of healthcare	Important	17	19	89.5	30	36	83.3	0.37	1, 12	0.554
	Not important	2	19	10.5	6	36	16.7			
Seeking or availability of information for decision-making	Important	17	19	89.5	31	36	86.1	0.13	1, 12	0.728
	Not important	2	19	10.5	5	36	13.9			
Personal wishes of parent	Important	19	19	100	34	36	94.4	Did not converge		
	Not important	0	19	0	2	36	5.6			

Qualitative Study

Sample Description

A total of 5 Euro-Americans (50%), 1 Chinese (10%), 2 Japanese (20%), and 2 Native Hawaiians (20%) participated in the structured telephone interviews. The interview participants were comprised of more females (n=7, 70%) than males (n=3, 30%). Interview participants were between the ages of 52 and 61 years of age, with the average age being 56.4 years (sd: 3.17 years). Themes were identified for the following six topics: Social Support Network,

Identification with Heritage Culture, Healthcare Decision-Making, Acquisition of Information from Health Professionals, Coping Strategies, and Fulfillment from Caregiving. In general, APIs and Euro-Americans were mostly similar for each of the topics and the respective themes. The themes and main findings from the qualitative analyses are reported for each of the six topics individually.

Range of Responses

Although the results of the qualitative analyses are non-generalizable by nature, the qualitative results show the wide diversity of caregiving and decision-making situations. Figure 3 is a word cloud generated from the transcripts for the Social Support Network questions. Words that appear more frequently in the transcripts are larger in size in the word cloud, while words that appear in closer proximity in the transcripts are shown in closer proximity in the word cloud. As shown in Figure 3, participants discussed a broad range of topics, including the concept of familial responsibility, the importance of independence for their parents, the role of in-laws in caregiving and decision-making, the role of formal nursing services, and the wishes of the parents.

Figure 3: Word cloud generated from responses to the Social Support Network questions

Social Support Network

The themes identified for Social Support Network are presented in Tables 14, 15, 16, and 17. The tables notate a main theme with a bolded font, with examples of supporting subthemes listed below in non-bolded font. For example, in Table 14, "Circumstantial delegation of caregiving duties" was a main theme that was used to cluster themes that were identified by the three independent researchers. The number of sources is a count of the number of participants that discussed the theme during their interview. Thus, 5 API and 5 Euro-American participants reported that their families employed circumstantial delegation of caregiving duties. The supporting subthemes that are not bolded were themes identified during interrater agreement. The subthemes were not mutually exclusive, and thus, participants could be coded for more than one subtheme.

As seen in Table 14, circumstantial delegation of caregiving duties emerged as one of the major themes discussed by all 10 interview participants, and thus, the theme was important for

both APIs and Euro-Americans. All interview participants reported that caregiving duties were delegated to specific family members based on some circumstantial considerations, such as an offspring's financial circumstances or medical knowledge/experience. One of the most salient circumstantial factors was the offspring's geographical location and housing accommodations. Often, when parents were choosing which offspring to move in with, the parents considered their affiliation and preference for potential communities (e.g., choosing to live in Hawai‘i over the mainland because of the good weather and friendly culture) and the offspring's housing accommodations (e.g., preference for more spacious homes and less physical obstructions). Although being less prevalent themes, caregiver burden and family dynamics were important considerations for some families, especially for families that had difficulty in maintaining cohesive family function while coordinating caregiving. All but one of the participants reported that delegation of caregiving duties occurred at the time that caregiving needs arose, rather than being pre-planned.

Table 14: Summary of themes for Social Support Network – Circumstantial Delegation

Social Support Network: Circumstantial Delegation			
Theme		Number of sources	
		EA	API
Circumstantial delegation of caregiving duties		5	5
	Delegation of caregiving duties based on children's financial circumstances	1	0
	Delegation of caregiving duties based on children's medical expertise	1	1
	Delegation of caregiving duties based on children's residence location and features	4	2
	Delegation of caregiving duties based on children's availability	2	4
	Delegation of caregiving duties based on children's caregiving strain	0	1
	Delegation of caregiving duties based on family dynamics or dysfunction	1	2
	Delegation of caregiving duties occurring only when parents are in need of caregiving	4	5

Two major themes in Social Support Network were related to the use of help from outside organizations and community members (summarized in Table 15). About half of the

participants reported that their families did not receive help from outside organizations and community members (including friends and neighbors), mainly since it was unnecessary for their situation; however, one participant reported that no outside help was received due to lack of connections with the outside community. For families that did receive help from outside organizations, friends, and community members, it was mainly for small tasks, such as transporting parents to the doctor's office or for information on later-life resources.

Table 15: Summary of themes for Social Support Network – Outside Help

Social Support Network: Outside Help			
Theme		Number of sources	
		EA	API
Family did not receive help from outside organizations and community members		2	2
	Family did not have many friends or connections with the community	1	0
	Outside help was not necessary	1	2
Family received help from outside organizations and community members		2	2
	Church members spent time with parent	0	1
	Neighbors helped parent with small tasks	1	0
	Friends helped parent with small tasks	1	0
	Friends supplied family with information about later-life resources	0	1
	Healthcare providers provided family with information about later-life resources	0	1
	Meals on Wheels	0	1

With respect to preparation for later-life healthcare and caregiving (Table 16), the majority of participants mentioned being ill-prepared for their parents' later-life healthcare and caregiving in some ways, while being prepared for their healthcare and caregiving in other ways. For both APIs and Euro-Americans, there was a major theme for difficulty with tending to parents' emotional needs, especially when a parent loses a spouse or develops a progressive degenerative neurological condition like Alzheimer's disease; however, the majority of participants were able to comfort their parents whenever the need arose.

Although some APIs and Euro-Americans reported a lack of long-term financial planning for later-life healthcare services by their parents, the API participants were less prepared. The Euro-American participants reported limited parental savings and investments as a result of large expenditures and lifestyle choices early in life, compared to APIs, who reported a severe neglect for long-term savings and investments by parents. Most families, however, did have some resources prepared to cover the expenses of later-life healthcare and caregiving. A few families were very well prepared, with substantial savings and investments; however, many families were only moderately prepared, having some form of insurance and modest savings. Such families were likely to report uncertainty with unforeseen large expenditures in the future (e.g., need for nursing home or surgery), and thus were likely to be coded for being both prepared and not prepared for later-life expenses. The themes for feeling prepared or not feeling prepared for caregiving included a broad range of responses, such as feeling unprepared for daily caregiving tasks and feeling mentally/emotionally prepared to take on the task of caregiving.

Table 16: Summary of themes for Social Support Network – Preparation

Social Support Network: Preparation			
Theme		Number of sources	
		EA	API
Family not prepared for later-life health and caregiving		3	4
	Children had difficulty tending to parents' emotional needs	3	2
	Lack of long-term financial planning by parent	1	1
	Participant did not feel prepared to be a caregiver	3	3
Family prepared for later-life health and caregiving		5	5
	Children tended to parents' emotional needs	4	3
	Children prepared for their parents' later-life healthcare and retirement	1	0
	Parents prepared for their later-life healthcare and retirement	5	4
	Participant felt prepared to be a caregiver	2	4

The last three major themes identified for Social Support Network involved the structure of the family caregiving and communication system (Table 17). The families of all interview

participants utilized a combination of self or spousal caregiving and offspring caregiving. For example, a family may have parents who live at home mostly independently, but children visit on occasion to help with small chores. Only APIs reported a reluctance to utilize formal nursing services and expressed a desire to keep caregiving duties within the family. In one example, an API parent explicitly communicated to the participant the desire to receive caregiving only from family members.

Most API and EA families had silent communication of caregiving expectations (i.e., parents not explicitly stating that they expect caregiving in later life, but rather the children perceive the expectation implicitly through cues such as a tradition for caregiving in the family or feeling that caregiving is the right thing to do). Most families were open to sharing information about their parents' healthcare between all family members. In these families, children were often present for major healthcare consultations with healthcare professionals or discussions between family members. About half of the participants had families that excluded some members from the communication network. For example, family members may be excluded from the decision-making and information-sharing process due to tension between family members. Participants of both API and Euro-American descent were open to discussing later-life healthcare and death, while a smaller subset of both groups formally discussed death and later-life decisions through Advance Directives, Do Not Resuscitate orders (DNR), and living wills.

Table 17: Summary of themes for Social Support Network – Caregiving and Communication

Social Support Network: Caregiving and Communication			
Theme		Number of sources	
		EA	API
Offspring caregiving and decision-making		5	5
	Caregiving duties handled by offspring	5	5
	Delegating caregiving roles to offspring	2	0
	Family was reluctant to use nursing home services	0	3
	Direct communication of caregiving expectation	0	1
	Silent communication of caregiving expectations	4	5
	Open to sharing information about health between family members	3	4
Self or spouse caregiving and decision-making		5	5
	Daily activities handled by self, spouse, or formal providers	4	4
	Family was open to nursing home services	2	3
	Concern with independence for parent	1	2
	No history or tradition of caregiving for grandparents	1	0
	Closed to sharing information about health between family members	2	2
Open to discuss death, dying, and later-life plans		2	3
	Formal later-life healthcare decision-making (Advance Directives, DNR, or will)	1	2

Identification with Heritage Culture

The themes identified for Identification with Heritage Culture are summarized in Tables 18 and 19. Several major themes in this topic were related to the participants' affiliations to API, Euro-American, and local Hawai‘i culture (Table 18). The major themes for this topic underscore the multicultural and heterogeneous nature of the Hawai‘i population. The large majority of interview participants reported an affiliation with API values, customs, and people. Most participants also reported an affiliation with western practices, customs, and people and with Hawai‘i's unique heterogeneous culture; however, most interview participants of API descent reported a stronger gravitation towards western culture than to API culture. Some Native Hawaiian participants in particular described the discontinuity in transmission of traditional Native Hawaiian beliefs and traditions due to the suppression of Native Hawaiian cultural practices in the 1900s. Some Euro-American participants who were in Hawai‘i for

multiple generations reported a stronger affiliation with Hawai‘i’s unique heterogeneous culture, compared to western beliefs and customs. As a result of this cultural heterogeneity, both APIs and Euro-Americans reported an affiliation to both collectivism and individualism; however, the cultural context for healthcare decision-making and caregiving was not always recognized by the participant. In one example, when a participant was asked about the role of culture in caregiving responsibility delegation, the participant reported that culture was not something they usually thought about explicitly, however, after further discussion, the participant partially attributed the family caregiving to cultural factors.

Table 18: Summary of themes for Identification with Heritage Culture – Cultural Affiliation

Identification with Heritage Culture: Cultural Affiliation		
Theme	Number of sources	
	EA	API
Affiliates with API values, customs, and people	5	2
Affiliates with western values, customs, and people	3	4
Affiliates with Hawai‘i’s unique heterogeneous culture	5	1
Values collectivism	3	2
Values individualism	1	2
Conflict or confusion attributed to multiple cultural values, practices, and people	1	1
Culture is not something consciously thought about	1	0

Themes concerning the openness of the participants and their families to alternative and western medicine are presented in Table 19. Most participants reported being open to alternative medicine, but included the caveat that alternative medicine is only appropriate under certain circumstances and must be properly researched. Many participants who reported no past utilization of alternative medicine mentioned that they had no reason to explore alternative medicine, since western medicine was sufficient. In some cases, there was a sentiment among APIs and Euro-Americans for the distrust of western medicine. One participant mentioned that

he/she did not trust cocktails of western medication, while another participant was cynical regarding the practices of pharmaceutical companies.

Table 19: Summary of themes for Identification with Heritage Culture – Medicine

Identification with Heritage Culture: Medicine			
Theme		Number of sources	
		EA	API
Open to alternative medicine or practices		5	4
	Family member open to or uses alternative medicine	3	2
	Participant open to or uses alternative medicine	4	3
Not open to alternative medicine or practices		4	5
	Family member closed to or does not use alternative medicine	4	5
	Participant closed to or does not use alternative medicine	2	4
Distrust of western medicine		1	1
	Distrust cocktails of western medications	1	0
	Distrust of the western pharmaceutical industry	0	1

Healthcare Decision-Making

Themes for Healthcare Decision-Making are summarized in Table 20. Nearly half of API and Euro-American participants mentioned that their families were open to discussions of death and dying; however, in one example, a participant reported a reluctance to discuss death and dying since it was difficult to come to terms with the fact that his/her parent was terminally ill. Contextual and circumstantial factors were major considerations for both API and Euro-American families when making healthcare decisions. Nearly all participants mentioned that the parents' best interest (mental and physical) was one of the central considerations for the healthcare decision.

When delegating caregiving duties, availability of formal and family caregivers was an important factor. For some API families, caregiver strain and family dysfunction was a central factor for the decision to place their parents in adult day care. Caregiving strain for these families included difficulty with balancing caregiving and professional responsibilities. The API

families experiencing caregiving strain and dysfunction also had issues with long-term financial planning by the parent, as discussed earlier. Nearly all families utilized a combination of group and individualistic decision-making and caregiving. For nearly all families, the final say in the healthcare decision was reserved for the parent, but often, children were solicited for their opinions. About half of participants from both API and EA groups shared information equally between all children in the family. A few API families excluded some offspring out of the decision-making process, in some cases due to family dysfunction. Only one API participant reported a reluctance to put his/her parent in a nursing home.

Table 20: Summary of themes for Healthcare Decision-Making

Healthcare Decision-Making			
Theme		Number of sources	
		EA	API
Open to discussions of later-life issues		2	2
Closed to discussions of later-life issues		1	0
Contextual factors for healthcare decision-making		3	5
	Availability of family caregivers and caregiver strain	0	2
	Availability of formal caregivers and healthcare providers	0	2
	Decision-making was based on what was best for parents' mental and physical health	3	5
Group decision-making and caregiving		4	4
	Deferring decision-making to specific offspring	0	2
	Soliciting opinions from offspring	2	1
	All children-generation family members having equal information	3	2
	Reluctance to use nursing home services	0	1
	Concern for preservation of harmony	0	1
Individualistic decision-making and caregiving		5	5
	Parental determination in healthcare decisions	5	4
	Disparity in information between parent- and children-generation family members	0	3
	Open to use nursing home services	1	1

Acquisition of Information from Health Professionals

Table 21 summarizes the themes for Acquisition of Information from Health Professionals. More than half of the interview participants reported having some difficulty with

acquiring information from their healthcare providers. Examples include (1) participants questioning the results communicated about a procedure undergone by their parent after becoming aware of inconsistent information, and (2) lack of information about later-life resources from healthcare providers (e.g., family only learned about hospice care after the death of a parent). Another theme was the perception that healthcare providers did not have enough time to adequately communicate with the participants and their family, which was attributed by the participants to the possibility of a shortage of geriatric healthcare providers in the community. Several participants mentioned that there was an information disparity between family members, with one participant mentioning the role of privacy (e.g., Health Insurance Portability and Accountability Act [HIPAA]) as a barrier to information sharing. A few participants were concerned with their parents' ability to ask questions during healthcare consultations, due to the parents' propensity to not ask questions or advanced age.

Table 21: Summary of themes for Acquisition of Information from Health Professionals

Acquisition of Information from Health Professionals			
Theme		Number of sources	
		EA	API
Difficulty with obtaining information from provider		3	3
	Healthcare provider giving inconsistent information	0	1
	Healthcare provider not giving enough information about later-life resources	2	0
	Healthcare provider not having enough time to adequately communicate with patients	1	0
	Healthcare provider not sufficiently discussing all treatment options	1	0
	Information disparity between family members	1	1
	Participants did independent research to fill in gaps	0	1
Parent has difficulty asking the right questions		2	0
	Parent not being the type of person to ask the right questions	1	0
	Parents' advanced age impeding ability to ask important questions	1	0
Positive communication process with provider		2	4

Coping Strategies

The themes identified for Coping Strategies are presented in Tables 22, 23, and 24. Interview participants had three general types of strategies for coping with the stresses of caregiving: external, internal, and social. For external strategies (see Table 22), most frequently, participants reported the use of physical exercise. Also, many participants used activities that removed themselves from their caregiving role (e.g., hobbies, work, and vacations). For several participants, alcohol was used for relaxation, including social and individual drinking.

Table 22: Summary of themes for Coping Strategies – External

Coping Strategies: External			
Theme		Number of sources	
		EA	API
External strategies for coping		4	4
	Drinking alcohol	1	1
	Physical exercise	4	4
	Taking breaks	2	2
	Work and hobbies	2	1

A few interview participants used internal strategies to cope with caregiver burden (see Table 23). It was important for some participants to give their parents as much decision-making power as possible, which relieved the participants from their decision-making responsibilities. One participant found it helpful to not take things personally, especially when taking care of a parent with dementia. Another participant reported that religion was a source of comfort while facing the challenges of later-life caregiving. Generally, these internal coping strategies were a form of cognitive reframing, where individuals change their perspectives to attain a more positive outlook on their situation.

Table 23: Summary of themes for Coping Strategies – Internal

Coping Strategies: Internal			
Theme		Number of sources	
		EA	API
Internal strategies for coping		3	0
	Giving parents as much decision-making power as possible	2	0
	Not taking things personally	1	0
	Religion	1	0

The majority of participants utilized social strategies to cope with the stresses of caregiving (see Table 24). Some participants requested family members to help with actual caregiving duties. This allowed for caregiving duties to be spread among more individuals, and was especially helpful for families with a large number of offspring. Other participants found it helpful to socialize with friends and family members, which provided another opportunity to remove themselves from the caregiving situation. Furthermore, socialization provided participants with the opportunity to share their thoughts and problems with others.

Table 24: Summary of themes for Coping Strategies – Social

Coping Strategies: Social			
Theme		Number of sources	
		EA	API
Social strategies for coping		4	4
	Getting advice from medical professionals	1	2
	Getting help with caregiving duties	2	1
	Relaxing with pets	1	0
	Socializing with friends and family	1	2

Fulfillment from Caregiving

The themes for Fulfillment from Caregiving are summarized in Table 25. All participants felt fulfilled in some way as a result of providing caregiving for their parents. The reasons for fulfillment varied greatly between individuals, including having the time to say final

goodbyes to a parent, learning and practicing new character values while being a caregiver, and teaching the participants' children about family values. Half of participants mentioned that caregiving was an opportunity to build a stronger bond with their parents. Only one participant mentioned that caregiving was foremost a duty, and fulfillment was just a byproduct of caregiving.

Table 15: Summary of themes for Fulfillment from Caregiving

Fulfillment from Caregiving			
Theme		Number of sources	
		EA	API
Caregiving is a duty and fulfillment is a second thought		0	1
Fulfillment from caregiving		5	5
	Fulfillment from building a stronger bond with parents	2	3
	Fulfillment from saying final goodbyes	1	0
	Fulfillment from feeling completed with duties as child	0	1
	Fulfillment from successfully overcoming the treatment	1	0
	Fulfillment form parents' enjoyment of small things	0	1
	Fulfillment from helping parent contribute to the family	0	1
	Fulfillment from giving back	3	1
	Fulfillment from teaching their own children new values	0	1
	Fulfillment from learning and practicing new character values	1	1

Discussion

Synthesis of Quantitative and Qualitative Findings

The quantitative-qualitative mixed methods approach provided contextual insights that allowed us to further explore the statistically significant differences between APIs and Euro-Americans for measures of caregiving expectation, caregiver burden, family dynamics, and healthcare decision-making. In the following subsections, we discuss the major quantitative findings and refer to qualitative themes that support or contradict these main results.

Ethno-racial Differences in Caregiving Expectations and Actual Caregiving Responsibilities

One of the major findings from the quantitative analyses was that APIs were significantly more likely to perceive an expectation to be a family caregiver, after controlling for extraneous demographic, socioeconomic, and parent health factors. This finding was consistent with the generalizations of API collectivism and filial piety in the qualitative literature (Hattori et al., 1991; Hofstede, 1984; Kitano & Kikumura, 1976; Long & Long, 1982; McLaughlin & Braun, 1998). Several qualitative findings from our analyses provided support for this quantitative result, while contributing additional insights into the possible mechanisms that lead to greater caregiving expectations for APIs. As discussed in the qualitative results section, there is a potential difference between Euro-Americans and APIs in terms of long-term financial preparation by parents. Although both APIs and Euro-Americans had one family each that reported a lack of long-term financial planning by their parents, the case for the API family was more severe. As a result of the neglect for long-term planning by the API parents, there were scarce financial resources available for formal nursing services when the need arose. Thus, the lack of long-term financial planning resulted not only in the need for financial contribution by offspring family members, but also in the need for actual caregiving tasks to be handled by offspring. Additionally, two themes from the Social Support Network component of the structured interview suggested a preference for family caregiving in APIs. One API participant reported that his/her parent explicitly communicated a preference to be cared for by family members only. Also, three of the five API interview participants reported a reluctance to put their parents in a nursing home, compared to zero of the five Euro-American participants. In addition, the Fulfillment from Caregiving topic had a theme for APIs to view caregiving as a duty. The trend ($p<0.1$) that Native Hawaiians are more likely to have actual caregiving

responsibilities compared to Euro-Americans may also be explained by possible differences in preparation and preference.

The quantitative analyses, however, failed to find statistically significant differences ($p<0.05$) between ethno-racial groups for measures of actual caregiving/decision-making duties. This suggested the possibility that greater prevalence of caregiving expectation for APIs does not necessarily imply greater prevalence of actual caregiving/decision-making duties for APIs. Subsequent statistical and power analyses were conducted to assess whether this possibility was realistic. Using a Type III generalized linear mixed models procedure with primary ethnic identification as the control, families as the random factor, expectation for caregiving as the explanatory variable, and actual caregiving/decision-making duties as the response variable, we found that expectation to be a caregiver for mother was a significant predictor for actual caregiving/decision-making duties for mother ($F[1, 23]=18.36$, $p=0.0003$, $n=91$) and expectation to be a caregiver for father was a significant predictor for actual caregiving/decision-making duties for father ($F[1, 18]=5.22$, $p=0.0347$, $n=83$). About 69.4% of participants who have an expectation to be a caregiver for their mother also had actual caregiving/decision-making responsibilities for their mother, whereas 20.4% of participants who did not have an expectation to be a caregiver for their mother had actual caregiving/decision-making responsibilities for their mother. For fathers, the rates were 46.9% and 22.8%, respectively. Although expectation for caregiving is not a perfect predictor for actual caregiving/decision-making duties, the additional analyses suggest that greater proportions of expectation for caregiving for APIs may imply greater rates of actual caregiving/decision-making by APIs. Assuming that the observed differences between APIs and Euro-Americans in actual caregiving/decision-making responsibility for mothers and fathers was accurate, the powers of the analyses were 0.16 and

0.08, respectively. Recall that power is the probability of rejecting the null hypothesis when in fact the alternative hypothesis is true. Thus, the insignificant findings for ethno-racial differences in actual caregiving/decision-making responsibilities is likely due to insufficient sample size to detect smaller effect sizes. Interestingly, significant ethno-racial differences existed for expectation to be a caregiver after controlling for measures of demographics, socioeconomic status, and parents' health, while the trend for ethno-racial differences between Native Hawaiians and Euro-Americans for actual caregiving/decision-making responsibilities became insignificant. This suggests that a large proportion of the variation in actual caregiving/decision-making responsibilities explained by primary ethnic identification was due to differences in demographic, socioeconomic, and parents' health factors.

The quantitative analyses also failed to find statistically significant differences between ethno-racial groups for caregiving expectations attributed to cultural reasons. Only a trend was found in the multiple comparisons for Native Hawaiians being more likely than Euro-Americans to have caregiving expectations for a cultural reason. The qualitative themes for Identification with Heritage Culture underscored Hawai‘i's unique heterogeneous cultural context. A total of 8 interview participants resided in Hawai‘i at the time of this study, while 2 participants lived in Hawai‘i sometime in the past. Although Euro-Americans and APIs both have their own unique cultural heritages, being in Hawai‘i's heterogeneous environment resulted in a cultural blending between Euro-American and API values, beliefs, and customs. Thus, many interview participants reported an affinity to both API collectivism and Euro-American individualism. Also, as mentioned by one interview participant, culture is not a construct consciously considered when making everyday decisions. Swidler (1986) explained that individuals do not choose the course for each of their actions by explicitly contemplating which course of action is

most consistent with their values. Rather, a person's actions is better thought of as packages of actions guided by culture, which can be conceptualized as a general way of organizing these packages and depends on habits, moods, and the views of the surrounding community (Swidler, 1986). Swidler's (1986) conceptualization of culture and actions implies that individuals are not likely to attribute their individual decisions (e.g., deciding to be a family caregiver) to cultural influences.

Ethno-racial Differences in Family Dynamics

In the unadjusted general linear mixed models, Native Hawaiians were shown to have significantly higher scores on the Family APGAR compared to Euro-Americans. Responses from the two Native Hawaiian interview participants supported this finding. The two Native Hawaiian participants both reported that most of their siblings provided caregiving collaboratively. Also, there was generally an open communication network between and among parents and siblings for healthcare issues. For major decisions (e.g., deciding who inherits the family home), parents and offspring formally discussed matters in person. Although all offspring were involved in the healthcare decision-making process, there was a consensus for both families that the parents had the final say in the decision. Also, both families encouraged their parents to live as independently as possible (e.g., encouraging parents to attend social events). Despite having occasional conflicts between siblings, issues were able to be discussed and resolved. The adjusted model for Family APGAR was insignificant, and thus, a large proportion of the variation in Family APGAR scores explained by primary ethnic identification was due to differences in demographic, socioeconomic, and parents' health factors.

Strengths and Limitations

This study was able to identify potential differences between Euro-Americans and APIs for measures of caregiving expectation, caregiver burden, family dynamics, and healthcare decision-making. Our sample included two Asian ethno-racial groups that comprise a large proportion of the population in Hawai‘i and the United States. Also, our sample included an understudied indigenous Pacific Islander population, which yielded findings that may be relevant to other indigenous populations in the United States (e.g., Alaska Natives and American Indians). Another strength of this study was the contextual insights on caregiving and healthcare decision-making offered by the mixed quantitative-qualitative approach. In addition to providing support to the quantitative findings, the themes identified in the qualitative analyses provide a range of potential areas for future research and possible healthcare policy/programs.

There are several limitations to this study. As a result of non-random sampling during the original 1970s recruitment, the convenience sample from the HFSC may not be representative of the general Hawai‘i and U.S. population. Families in the original 1970s HFSC cohort were of a relatively higher socioeconomic status than the general Hawai‘i population at that time (Onoye et al., 2014). An additional level of selection bias occurred during the stratified sampling for survey participants from the HFSC cohort. As shown in the sample description, survey participants were more likely to have a bachelor’s or graduate degree compared to the general Hawai‘i population (U.S. Census Bureau, 2014b). A slightly larger proportion of individuals in our survey sample had individual incomes above $39,000, compared to the Hawai‘i population (U.S. Census Bureau, 2014a). Also, children-generation HFSC participants with high levels of caregiver burden may have opted out of the study due to constraints on time.

Although qualitative analyses are not meant to be representative of the population, it provided valuable insights into the range of possible family circumstances.

Another limitation of this study was the potentially inaccurate information provided by participants through self-report and introspection. For example, survey participants may not have an accurate recollection of their parents' recent healthcare utilization, health conditions, and funding sources for healthcare services. A third limitation to this study was the small sample size for both the survey and the structured interviews. Smaller sample sizes afforded less power to identify statistically significant differences between ethno-racial groups for measures of caregiving, family dynamics, and decision-making. Although the effect size was notable for some response variables (e.g., APIs having larger BSFC-s scores than Euro-Americans), small p-values were not obtained since the sample size for each ethno-racial group was small. Small sample size was a major issue for the analyses of BSFC-s scores and decision-making factors, since only about half of participants completed these sections.

Also, this study did not include measures for level of affiliation to Euro-American and API culture. As demonstrated in the qualitative component of this study, primary ethno-racial identification was insufficient for measuring cultural affiliation because of the culture sharing between APIs and Euro-Americans in Hawai‘i. Lastly, the context of caregiving and healthcare decision-making varied greatly between families, which made it difficult to make comparisons between ethno-racial groups. For example, in the section of the survey where participants were asked to rate the importance of healthcare decision-making factors for a recent healthcare decision, the type of health complication varied greatly between survey participants and was not controlled for. Despite these limitations, the findings from this study should be pertinent to

middle- and higher-income Chinese, Japanese, Native Hawaiian, and Euro-American families in Hawai‘i.

Additional Insights and Areas for Future Research

In addition to providing support for the quantitative findings, the qualitative component of this study provided new insights into caregiving and later-life healthcare decision-making that can guide future research endeavors. One of the major themes from the Social Support Network topic was the circumstantial delegation of caregiving duties. Nine out of the ten interview participants reported that the delegation of caregiving duties only occurred when caregiving for parents became necessary, while all families mentioned that circumstantial factors played a role in distributing caregiving duties among family members. Furthermore, almost all participants reported silent communication of caregiving expectations, implying that there were no explicit discussions about later-life caregiving and roles between parents and their offspring. Additionally, some participants reported financial strain due to lack of long-term financial planning by their parents. Lack of long-term planning and preparation for caregiving may be a contributor to caregiver burden.

In future studies, research on the prevalence of last-minute caregiving responsibility delegation and lack of long-term financial planning would inform researchers, policy makers, and clinicians of the pervasiveness of this issue. Next, the correlation between long-term planning and caregiver burden can be measured, which would ascertain the usefulness of outreach programs that promote thoughtful delegation of caregiving roles and financial planning for later-life healthcare. Also, comparisons between demographic groups for measures of long-term financial planning and caregiving delegation could help identify groups at risk for caregiver burden. Since some ethno-racial groups may think of caregiving as part of their culture, certain

groups may find outreach programs that promote long-term planning by parents to be offensive, and thus, research into the perception of long-term planning for later-life healthcare and caregiving would be useful for developing culturally-sensitive interventions.

Interview participants with a large number of siblings seemed to fare better with the financial, social, and physical stresses of caregiving. Since the participants in this study were from the Baby Boomer generation, their families were generally had a larger number of offspring. However, as is well known, the average family size is decreasing in developed nations throughout the world, including the United States. The average family size in the United States in 2010 was 3.14 individuals (U.S. Census Bureau, 2010b). For future healthcare policy planning in Hawai‘i and the United States, it may be useful to measure the correlation between caregiver burden and family size. If the two variables are negatively correlated, we may expect to see an increase in caregiver burden for families throughout the United States.

One interview participant reported that his/her parents' primary care provider did not have enough time during healthcare consultations to adequately communicate all important information. The participant speculated that this time constraint may be due to the shortage of geriatric providers in the United States and changes to the U.S. healthcare system. Although this evidence is anecdotal in nature, it is an example of the possible human tolls that would result from healthcare workforce shortages. Such findings highlight the need for unbiased estimations of healthcare workforce shortages with confidence intervals, which would be useful for informing policy makers on the number of medical school seats and geriatric residency positions that are needed in the future to increase workforce capacity.

Several participants reported that their parents' healthcare providers did not sufficiently inform their families on the later-life resources available in the community. As mentioned

previously, some participants only learned about hospice care after the death of a parent. Many interview participants learned about hospice care through recommendations by friends and family members and not through their providers. To guide the development of medical education, it would be helpful to assess healthcare providers' competency regarding their community's later-life healthcare resources. Furthermore, future research should measure the proportion of healthcare providers who actively supply patients with information about community resources, such as hospice. Organizations such as Kōkua Mau (http://www.kokuamau.org/) compile valuable information on hospice and palliative care resources in the state of Hawai‘i and can be used as the source of questions that assesses healthcare providers knowledge of Hawai‘i's later-life healthcare resources.

Implications for Policy and Program Recommendations

The quantitative and qualitative findings from this study may potentially inform policy and program recommendations intended to reduce caregiver burden and develop more culturally-sensitive and efficient healthcare services. Some potential recommendations are listed and briefly described below.

Basic Elderly Care Education for Informal Caregivers: Informal family caregivers will likely continue to be integral members of the elderly care team; however, as demonstrated by our qualitative results, family caregivers often feel unprepared for at least some aspect of caregiving. It will be important to provide family caregivers with adequate knowledge and resources to provide caregiving safely. Consistent with the Hawai‘i State Plan on Aging: 2011-2015 (Hawai‘i State Department of Health Executive Office on Aging, 2011), educating caregivers on how to make the home safe for seniors and how to prevent falls (Hawai‘i State Department of Health Executive Office on Aging, 2013a) may be especially helpful for APIs, who generally

prefer caregiving duties to be handled by family members. Also, as shown in our qualitative analyses, family caregivers had a particularly difficult time caregiving for parents with Alzheimer's and related dementias. The Hawai'i 2025: State Plan on Alzheimer's Disease & Related Dementias summarizes strategies for supporting individuals with Alzheimer's disease and related dementias (Hawai'i State Department of Health Executive Office on Aging, 2013b). Culturally-sensitive and affordable educational materials (e.g., how-to videos translated into languages predominant in Hawai'i) still need to be developed, and efficient distribution systems for these materials need to be identified (Hawai'i State Department of Health Executive Office on Aging, 2013b). Evidence-based dementia caregiving trainings in Hawai'i include the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) and What's Next, which were described in the Hawai'i 2025: State Plan on Alzheimer's Disease & Related Dementias (Hawai'i State Department of Health Executive Office on Aging, 2013b).

Incorporating Later-Life Community Resources into Medical Education: A common issue among interview participants was the lack of communication by primary care providers on later-life healthcare resources. A paradigm shift where primary care providers adopt the role as the communicators of community resources could improve patient care in Hawai'i and the United States. This shift may be accomplished through incorporating community resources into medical school and residency curricula and in Continuing Medical Education (CME). Aspects of the John A. Burns School of Medicine's (JABSOM) MD curriculum serve as examples for the incorporation of community resources into medical education, such as JABSOM's year-long community health program that requires first-year medical students to contribute to a local community health organization. Furthermore, organizations like Kōkua Mau (http://www.kokuamau.org/), which are supported by experts in hospice and palliative care and

compile information on community resources, can serve as the source of information for a later-life healthcare resource curriculum.

Mental Health Resources for Family Caregivers: Since family caregivers are at risk for burnout, mental health services may be useful for maintaining the mental well-being of caregivers. The development of screening protocols, using measurement tools like the Modified Caregiver Stress Index, by healthcare providers may be useful for identifying caregivers at risk for high levels of caregiver burden. This may be especially beneficial for caregivers with a mental health condition. The Hawai‘i State Plan on Aging: 2011-2015 described protocols that can help connect family caregivers with mental health services, such as support groups and counseling (Hawai‘i State Department of Health Executive Office on Aging, 2011). Furthermore, healthcare providers have the option of prescribing intervention programs to caregivers experiencing caregiver burden. In the past 30 years, over 200 dementia caregiver interventions have been shown to be effective through randomized control trials (Gitlin, Marx, Stanley, & Hodgson, 2015). One such program, REACH II, is currently being advocated by the Hawai‘i State Department of Health Executive Office of Aging (2013b). Many of the 200+ programs, however, have yet to undergo translational research and implementation, due to issues such as limited funding (Gitlin et al., 2015). Also, since translational research using minority ethno-racial groups are scarce, further research needs to be conducted to determine the efficacy of these intervention programs for Hawai‘i’s diverse population.

Long-term Financial Planning and Caregiving Role Delegation: Two major themes from the qualitative analyses were a circumstantial delegation of caregiving duties and a lack of long-term financial planning, which may be more severe for APIs. The implementation of formal later-life planning (e.g., Advance Directives and DNRs) has been successful in the United States.

Kōkua Mau compiles the most recent protocols for formal later-life healthcare planning, including Advance Directives and Physician Orders for Life-Sustaining Treatment (POLST). Including two additional components (financial planning and discussions of caregiving roles) into formal later-life planning could be a preventive strategy for caregiver burden.

Culturally-Sensitive Advance Care Planning: There is a need for Advance Care Planning protocols to be more culturally sensitive. Despite the large cultural diversity in Hawai‘i and the United States, standard practices for Advance Directives and Advance Care Planning do not take into consideration cultural differences (Zager & Yancy, 2011). A literature review of publications that discussed Advance Directives and Advance Care Planning was conducted by Zager and Yancy (2011), who summarized key points from the reviewed publications to provide recommendations for culturally-sensitive Advance Care Planning protocols. The authors recommended the incorporation of additional questions in the Advance Directives form, such as "What information would be helpful for you to share with me about you or your family views or cultural/religious views that might affect/dictate your medical care?" The Advance Directive forms used by some large hospitals in Hawai‘i, do not currently contain such phrases but could become more culturally sensitive by incorporating the changes endorsed by Zager and Yancy (2011). Furthermore, Zager and Yancy (2011) discussed the importance of educating healthcare providers on the values and beliefs of the various cultures that exist in the areas they practice.

Cultural Competency in Healthcare Professionals: Although cultural traditions and alternative healing practices were ranked much lower on the list of decision-making considerations, approximately one-fourth of survey participants still scored it as an important factor in their healthcare decisions. Furthermore, almost all interview participants believe that alternative medicine can be a complement to western medications under the right circumstances.

Healthcare providers should have a basic understanding of the cultural traditions in their communities and be prepared to work with complementary and alternative medicine practitioners. Reluctance by medical providers to collaborate with complementary and alternative medicine practitioners may create an additional barrier of access to healthcare services for some patients. The integration of cultural topics (e.g., Lā‘au Lapa‘au) into medical school education and graduate medical education would help providers build rapport with patients from culturally-diverse backgrounds.

Conclusions

With the disproportionately large growth rate of the geriatric population, compared to the growth rate of the population most likely to be family caregivers, the sufficiency of the geriatric care workforce (including both formal and informal caregivers) will continue to be a major concern in the United States. This study showed that select ethno-racial groups may be more likely to have caregiving expectations and duties. Specifically, APIs were significantly more likely to have an expectation to be a family caregiver compared to Euro-Americans. Also, there was a trend for higher rates of actual caregiving/decision-making duties for Native Hawaiians compared to Euro-Americans. The qualitative component of this study offered potential explanations for these differences, including a preference for caregiving by family members among APIs. To better inform healthcare policy in the future, several areas for future research were proposed, mainly to identify protective and risk factors for caregiver burden. The identified differences and similarities between ethno-racial groups for measures of caregiving expectation and duties may potentially inform policy and program recommendations designed to reduce caregiver burden in Hawai‘i and the United States.

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Appendices

Appendix A: Survey Form

Hawai'i Family Study of Cognition Survey

Thank you for your participation! ***If at any time during the survey, you feel discomfort or distressed from questions that may be sensitive in nature or topic, you may skip the question or stop your participation in the study.***

Section 1 – Please answer these questions about yourself.

1) What is your gender? □ Male □ Female □ Other
2) What is your age in years? _____
3) What is your current marital status? □ Single □ In a Relationship □ Married □ Divorced/Separated □ Widowed
4) Are/were you in the military, reserve, or guard? □ Yes □ No
5) Are you a veteran? □ Yes □ No
6) Growing up, were either of your parents in the military? □ Yes □ No

7) Which race/ethnic group(s) do you identify with? (Check all that apply.)

☐ Alaskan Native/American Indian	☐ Chinese	☐ Native Hawaiian
☐ Asian Indian	☐ Filipino	☐ Other Pacific Islander
☐ Black/African American	☐ Hispanic or Latino	☐ Portuguese
☐ White/Caucasian	☐ Japanese	☐ Vietnamese
	☐ Korean	☐ Other: _____

8) From Question 7 above, please **circle** the race/ethnic group that you **most** identify with. (Circle only one.)

9) What is your current employment status?
□ Full-time □ Part-time □ Seasonal □ Unemployed □ Retired

10) What is your current occupation (or last major occupation if retired or unemployed)?
_____

11) What is your highest level of education?

☐ Doctoral or Professional Degree	☐ Some College
☐ Master's Degree	☐ High School Graduate
☐ Bachelor's Degree	☐ Some High School
☐ Associate's Degree	☐ Intermediate School or Less
☐ Trade, Technical or Business School Degree	

12) Considering that the median annual personal income in the United States for an individual adult (above 25 years old) is $39,000, or for a household of married adults is $62,000 are you (or your household):
□ Well above the median □ Above the median □ At the median □ Below the median □ Well below the median

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Section 2 - This section is for your ***parents'*** healthcare utilization. If a parent has passed away, please describe his or her health and healthcare utilization in the time before their passing.

1) Are your parents currently still living?

Mother	**Father**
☐ Currently alive	☐ Currently alive
☐ Passed away	☐ Passed away

2) In the past month, have your parents gone to see a health professional for a health concern other than a routine check-up?

Mother	**Father**
☐ Yes	☐ Yes
☐ No	☐ No
☐ Don't know	☐ Don't know

3) Are your parents living in a nursing home/facility or have nursing help/assistance in their own home?

Mother	**Father**
☐ Yes	☐ Yes
☐ No	☐ No
☐ Don't know	☐ Don't know

4) Please check any health issues that your parents have experienced in the past year. (Check all that apply.)

Mother

- ☐ Arthritis or Rheumatism
- ☐ Back or neck problem
- ☐ Fractures, bone/joint injury
- ☐ Walking problem
- ☐ Lung or breathing problem
- ☐ Hearing problem
- ☐ Eye or vision problem
- ☐ Heart problem
- ☐ Stroke problem
- ☐ Hypertension/high blood pressure
- ☐ Diabetes
- ☐ Cancer
- ☐ Depression, anxiety, or emotional problem
- ☐ Dementia (for example, Alzheimer's)
- ☐ Other:_____

Father

- ☐ Arthritis or Rheumatism
- ☐ Back or neck problem
- ☐ Fractures, bone/joint injury
- ☐ Walking problem
- ☐ Lung or breathing problem
- ☐ Hearing problem
- ☐ Eye or vision problem
- ☐ Heart problem
- ☐ Stroke problem
- ☐ Hypertension/high blood pressure
- ☐ Diabetes
- ☐ Cancer
- ☐ Depression, anxiety, or emotional problem
- ☐ Dementia (for example, Alzheimer's)
- ☐ Other:_____

5) In the past year, how many nights did your parent stay in the hospital?

Mother

- ☐ None
- ☐ 1-5 nights
- ☐ 6-10 nights
- ☐ More than 10 nights
- ☐ Don't know

Father

- ☐ None
- ☐ 1-5 nights
- ☐ 6-10 nights
- ☐ More than 10 nights
- ☐ Don't know

6) In the past year, how many times have your parents visited the emergency room?

Mother

- ☐ None
- ☐ 1 time
- ☐ 2-3 times
- ☐ More than 3 times
- ☐ Don't know

Father

- ☐ None
- ☐ 1 time
- ☐ 2-3 times
- ☐ More than 3 times
- ☐ Don't know

7) In the past year, have your parents undergone a surgical procedure?

Mother

- ☐ Yes
- ☐ No
- ☐ Don't know

Father

- ☐ Yes
- ☐ No
- ☐ Don't know

8) Which financial sources were utilized by your parents to pay for their medical or healthcare expenses? (Check all that apply.)

Mother

- ☐ Private insurance
- ☐ Investments, savings, or assets
- ☐ Social Security or other income
- ☐ Medicare
- ☐ Medicaid
- ☐ Credit or loans
- ☐ Immediate family members' income or assets
- ☐ Other:_____

Father

- ☐ Private insurance
- ☐ Investments, savings, or assets
- ☐ Social Security or other income
- ☐ Medicare
- ☐ Medicaid
- ☐ Credit or loans
- ☐ Immediate family members' income or assets
- ☐ Other:_____

Section 3 - This section asks about your family dynamics. If a parent has passed away, please describe the family situation during the time before their passing.

1) Do your parents expect that you will support their healthcare issues financially, make (or help make) healthcare decisions for them, and/or provide caregiving for them?

Mother: □ Yes □ No **Father:** □ Yes □ No

2) Does this expectation to be a caregiver and to support your parents come from your ethno-cultural background?

□ Yes □No □No expectation for caregiving

3) If yes to the above, please indicate which ethno-cultural group(s): _____

4) How geographically close are you to your parents?

Mother	**Father**
☐ In the same household	☐ In the same household
☐ Within several miles	☐ Within several miles
☐ In the same state or area but with more than a 30 minute drive	☐ In the same state or area but with more than a 30 minute drive
☐ In a separate state	☐ In a separate state
☐ In a different country	☐ In a different country

5) How often do you communicate with your parents? (For example, by mail, email, phone, visits, etc.)

Mother	**Father**
☐ Almost daily	☐ Almost daily
☐ Almost weekly	☐ Almost weekly
☐ Almost monthly	☐ Almost monthly
☐ 3-4 times a year	☐ 3-4 times a year
☐ Once or twice a year	☐ Once or twice a year
☐ Less than once a year	☐ Less than once a year

6) For each statement, check the box that best represents your family

		Almost always	**Some of the time**	**Hardly ever**
A)	Our family helps each other during times of health concerns or crisis	□	□	□
B)	Our family is able to discuss healthcare concerns and shares the healthcare decision-making process among family members	□	□	□
C)	Our family is supportive of personal wishes and individual decisions for healthcare	□	□	□
D)	My family expresses affection and responds with anger, sorrow, and love during times of health concerns or crisis	□	□	□
E)	Our family is able to share time, space and wealth during times of healthcare concerns or crisis	□	□	□

Section 4 - This section asks about your role as a caregiver for your parents.

1) Were you involved in making healthcare decisions and/or providing caregiving for your parents? If yes then continue to the questions below. If no, please skip to the next section.

Mother: □ Yes □ No **Father:** □ Yes □ No

2) For each statement, check the appropriate box

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
A)	My life satisfaction has suffered because of the care or health decision-making	□	□	□	□	□
B)	I often feel physically exhausted	□	□	□	□	□
C)	From time to time, I wish I could "run away" from the situation I am in	□	□	□	□	□
D)	Sometimes I don't really feel like "myself"	□	□	□	□	□
E)	Since I have been a caregiver, my financial situation has decreased	□	□	□	□	□
F)	My health is affected by the care situation	□	□	□	□	□
G)	The care takes a lot of my own strength	□	□	□	□	□

		Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
H)	I feel torn between the demands of my environment (such as family) and the demands of the care	□	□	□	□	□

I)	I am worried about my future because of the care I give	□	□	□	□	□
J)	My relationship with other family members, relatives, friends, and acquaintances are suffering as a result of the care	□	□	□	□	□

Section 5 - This section asks your opinion about a recent healthcare decision for your parent.

1. What is the most recent significant healthcare decision made for a parent (for example: deciding to undergo a surgical procedure or placement into a nursing home)? Fill in the space below:
   _____

2. Which parent was this healthcare decision for? □ Mother □ Father

3. For the healthcare decision mentioned above, please rate the importance of each of following factors for your parent's healthcare decision. In the space provided, briefly describe how the factor affected the decision-making process. If needed, you may also fill in the two remaining boxes at the very bottom (K and L) with factors that were important to the healthcare decision, but were not mentioned.

Factors	**Not Important**	**Moderately Important**	**Very Important**
A) Financial resources and cost of healthcare	□	□	□
Please describe: _____			
B) Healthcare professional recommendations or expectations	□	□	□
Please describe: _____			
C) Risks of procedure	□	□	□
Please describe: _____			
D) Burden on family	□	□	□
Please describe: _____			
E) Opinions and preferences of family members	□	□	□
Please describe: _____			
F) Cultural traditions/values or alternative healing practices	□	□	□
Please describe: _____			
G) Trust in healthcare team or system	□	□	□
Please describe: _____			
H) Availability of healthcare	□	□	□
Please describe:_____			
I) Seeking or availability of information for decision-making	□	□	□
Please describe: _____			
J) Personal wishes of parent	□	□	□
Please describe: _____			
K) Other:	□	□	□
Please describe: _____			
L) Other:	□	□	□
Please describe: _____			

Appendix B: Interview Form

Phase 8 Interview

Section 1: Family Dynamics

Adaption	Question 1: How have you and your siblings helped your parents when they had health concerns or crisis? How about friends and community agencies?
Partnership	Question 2: How do family members communicate with each other about your parents' medical care?
Growth	Question 3: How have you and your siblings helped your parents in developing independent lifestyles?
Affection	Question 4: How have you and your siblings reacted to your parents when they expressed feelings like affection and sadness during a health concern or crisis?
Resolve	Question 5: How does your family share time, space, and money during a parents' healthcare concern or crisis?

Section 2: Delegation of Caregiving Duties

Question 6: What led you to believe that you were expected to be a caregiver for your mother?

Question 7: What led you to believe that you were expected to be a caregiver for your father?
Question 8: How was caregiving responsibilities for your parents delegated among family members?

Section 3: Caregiving Readiness

Question 9: How comfortable and prepared do you feel in providing caregiving for your parents? Explain.
Question 10: How did your family financially prepared for your parents' elderly healthcare services?

Section 4: Cultural Identity

Question 11: How strongly do you identify with the western culture and the _____ (primary ethnic identity reported in previous survey) culture? Why?
Question 12: What are your feelings towards traditional/alternative medicine?

Section 5: Healthcare Decision Making

Question 13: What was the entire decision-making process for the decision to _____ _____ (healthcare decision provided in the previous survey)?
Question 14: Have your healthcare providers adequately kept you informed on important health information about your parents throughout the healthcare decision? Explain.

Section 6: Benefits/Coping with Caregiver Burden

Question 15: What strategies did you use to handle emotional, mental, and physical stress associated with your caregiving responsibilities? Does a sense of fulfillment help you provide caregiving for your parents?

Appendix C: Summary of Variables used in Analyses

Explanatory Categorical Variables				
Variable	***Category 1***	***Category 2***	***Category 3***	***Category 4***
Participants' primary ethnic identification	Euro-American	Japanese American	Chinese American	Native Hawaiian

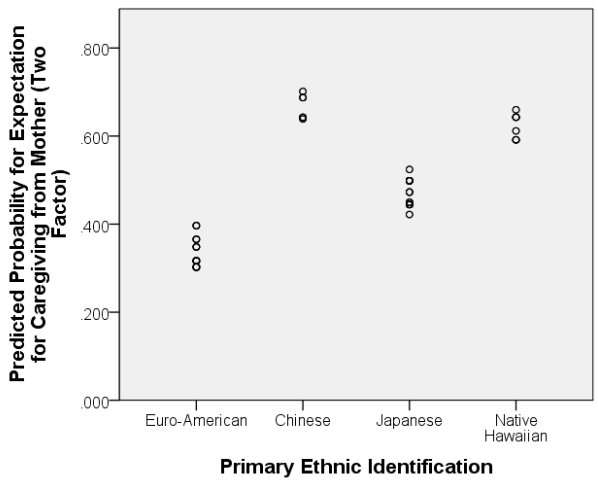
Control Variables			
Variable	***Category 1***	***Category 2***	***Category 3***
Participants' gender	Male	Female	
Parents' military history	Parent was in military	Parent was not in military	
Participants' annual income	Above $39,000 or well above $39,000	At $39,000, below $39,000, or well below $39,000	
Participants' highest educational attainment	Doctoral or professional degree or Master's degree	Bachelor's degree	Associate's degree, trade, technical or business school degree, some college, high school graduate, some high school, or intermediate school or less
Mother's emergency room utilization in the past year	1 time, 2-3 times, or more than 3 times	No utilization	
Father's emergency room utilization in the past year	1 time, 2-3 times, or more than 3 times	No utilization	
Parent's emergency room utilization in the past year	One or both parents visited the emergency room at least once	Neither parent visited the emergency room	
Mother's government insurance utilization	Mother used Medicare or Medicaid for healthcare expenses	Mother did not use Medicare or Medicaid for healthcare expenses	
Father's government insurance utilization	Father used Medicare or Medicaid for healthcare expenses	Father did not use Medicare or Medicaid for healthcare expenses	
Parents' government insurance utilization	One or both parents used Medicare or Medicaid for healthcare expenses	Neither parent used Medicare or Medicaid for healthcare expenses	
Mother has a mental health condition	Mother has depression, anxiety, emotional problem, or dementia	Mother does not have depression, anxiety, emotional problem, or dementia	
Father has a mental health problem	Father has depression, anxiety, emotional problem, or dementia	Father does not have depression, anxiety, emotional problem, or dementia	
Parent has mental health problem	One or both parents has depression, anxiety, emotional problem, or dementia	Neither parent has depression, anxiety, emotional problem, or dementia	
Participants' age	Participant's self-reported age in years		
Family (random factor)	Each family was assigned a family number for the analyses.		

Response Categorical Variables		
Variable	***Category 1***	***Category 2***
Participant has an expectation to provide caregiving for his/her mother	Yes	No
Participant has an expectation to provide caregiving for his/her father	Yes	No
Participant has an expectation to be a caregiver for his/her parents for a cultural reason	Yes	No
Participant has actual caregiving or decision-making responsibilities for his/her mother	Yes	No
Participant has actual caregiving or decision-making responsibilities for his/her father	Yes	No
Participants' geographic proximity to mother	In the same state or area but with no more than a 30-minute drive away, within several miles, or within the same household	In a separate state or different country
Participants' geographic proximity to father	In the same state or area but with no more than a 30-minute drive away, within several miles, or within the same household	In a separate state or different country
Participants' frequency of communication with mother	Communicates with mother almost daily or almost weekly	Communicates with mother almost monthly, 3-4 times a year, once or twice a year, or less than once a year
Participants' frequency of communication with father	Communicates with father almost daily or almost weekly	Communicates with father almost monthly, 3-4 times a year, once or twice a year, or less than once a year
Decision-making factor: Financial resources and cost of healthcare	Moderately important or very important	Not important
Decision-making factor: Healthcare professional recommendation or expectation	Moderately important or very important	Not important
Decision-making factor: Risk of procedure	Moderately important or very important	Not important
Decision-making factor: Burden on family	Moderately important or very important	Not important
Decision-making factor: Opinions and preferences of family members	Moderately important or very important	Not important
Decision-making factor: Cultural traditions/values or alternative healing practices	Moderately important or very important	Not important
Decision-making factor: Trust in the healthcare team or system	Moderately important or very important	Not important
Decision-making factor: Availability of healthcare	Moderately important or very important	Not important
Decision-making factor: Seeking or availability of information for decision-making	Moderately important or very important	Not important
Decision-making factor: Personal wishes of parent	Moderately important or very important	Not important

Response Scale Variables	
Variable Name	***Description***
Family APGAR cubed	Cubed total score for the APGAR Scale
BSFC-s	Total score for the BSFC-s Scale

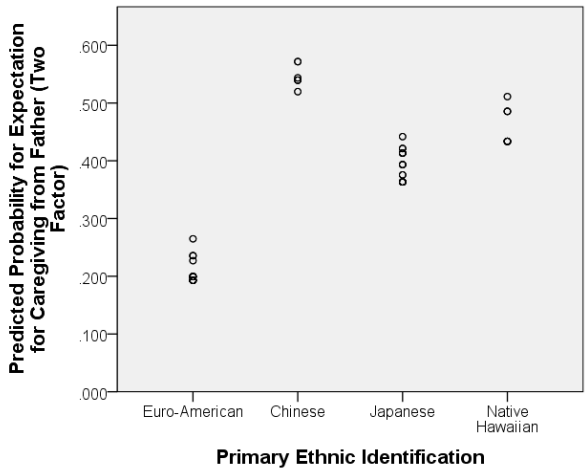
Appendix D: Model Diagnostics

First, the associations between primary ethnic identification and the other explanatory variables that were used in the multiple regression models were assessed using Chi-Square Tests and analyses of variance (ANOVA) (summarized in Tables 5 and 6). The assumptions of the unadjusted generalized linear mixed models are independence and equal variance for the random effect. Since the families were randomly selected from their respective strata, the assumption of independence should be acceptable. To determine if the equal variance of the random effect assumption was appropriate, the predicted probabilities for each observation was generated. The standard deviation for the predicted probabilities was calculated for each ethno-racial group. Equal variance was considered to be a safe assumption if the largest standard deviation out of the four ethno-racial groups was no more than two times greater than the smallest standard deviation. The scatter plots and standard deviations for all of the unadjusted generalized linear mixed models were presented below. The equal variance assumption was appropriate, unless otherwise noted.



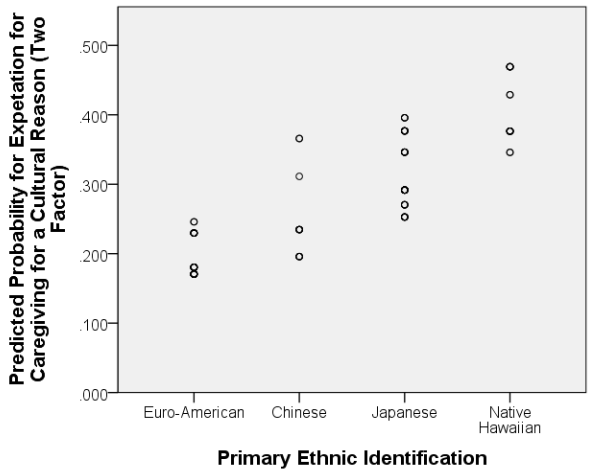
Response variable:
Expectation to be a caregiver for mother

Ethnicity	Standard Deviation
Euro-American	0.033
Chinese	0.027
Japanese	0.029
Native Hawaiian	0.027



Response variable:
Expectation to be a caregiver for father

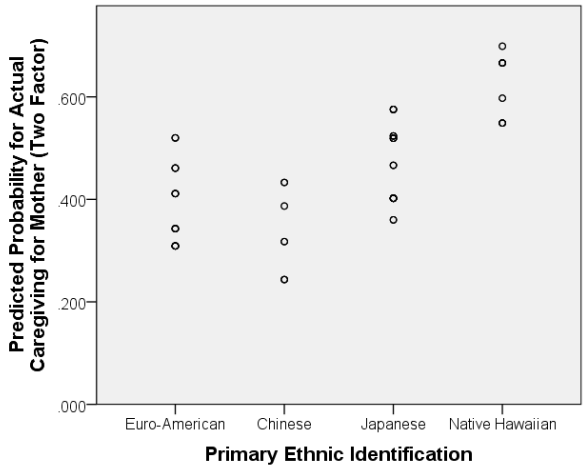
Ethnicity	Standard Deviation
Euro-American	0.021
Chinese	0.019
Japanese	0.026
Native Hawaiian	0.032



Response Variable:
Caregiving expectation for cultural reason

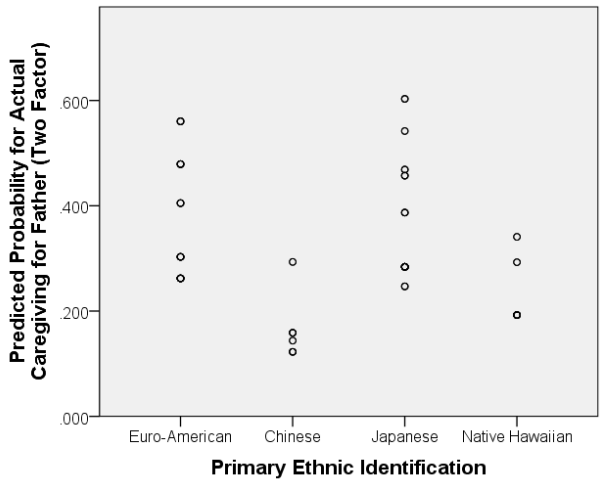
Assumption validity:
Largest standard deviation was only slightly greater than two times the smallest

Ethnicity	Standard Deviation
Euro-American	0.028
Chinese	0.063
Japanese	0.049
Native Hawaiian	0.049



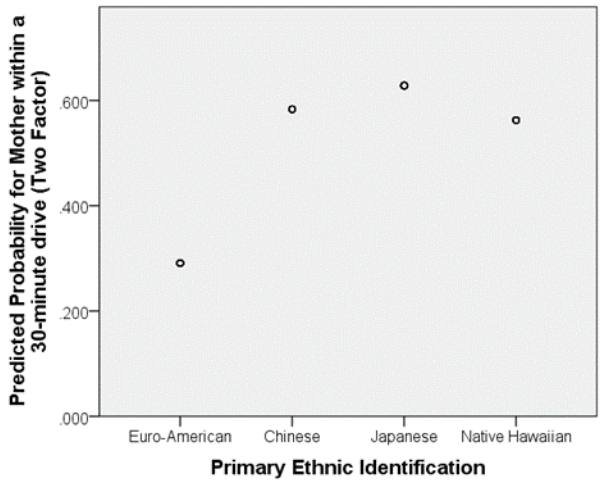
Response Variable:
Actual caregiving/decision-making for mother

Ethnicity	Standard Deviation
Euro-American	0.076
Chinese	0.079
Japanese	0.073
Native Hawaiian	0.060



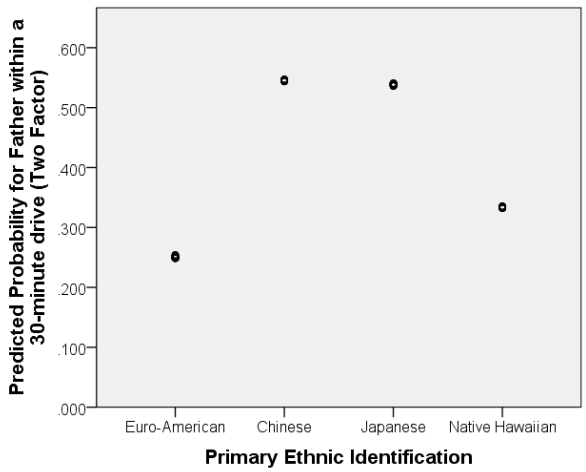
Response variable:
Actual caregiving/decision-making for father

Ethnicity	Standard Deviation
Euro-American	0.111
Chinese	0.061
Japanese	0.112
Native Hawaiian	0.060



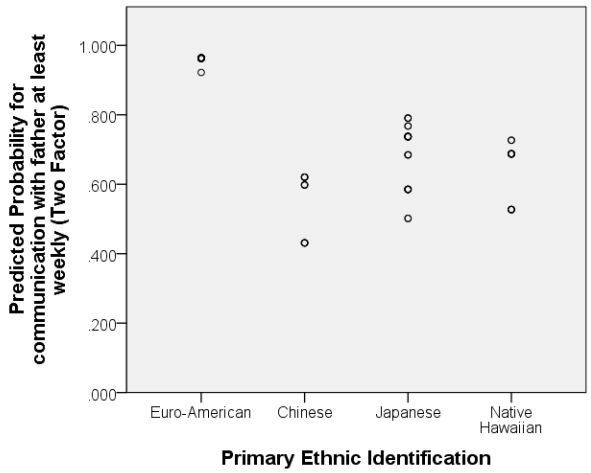
Response variable:
Geographic proximity to mother

Ethnicity	Standard Deviation
Euro-American	1.27×10^{-11}
Chinese	9.30×10^{-12}
Japanese	1.02×10^{-11}
Native Hawaiian	1.30×10^{-11}



Response variable:
Geographic proximity to father

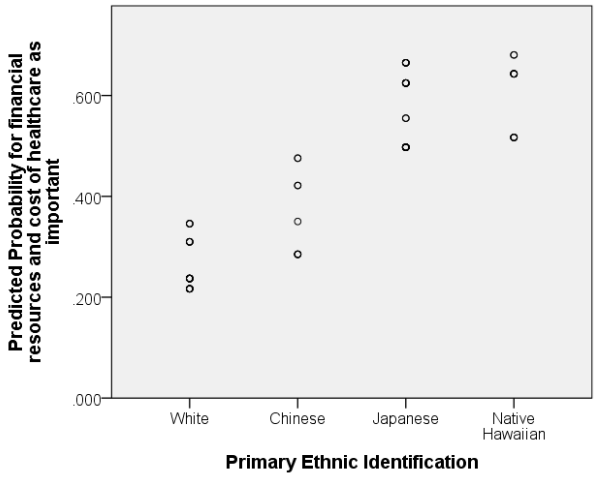
Ethnicity	Standard Deviation
Euro-American	0.0017
Chinese	0.0016
Japanese	0.0018
Native Hawaiian	0.0016



Response variable:
Frequency of communication with father

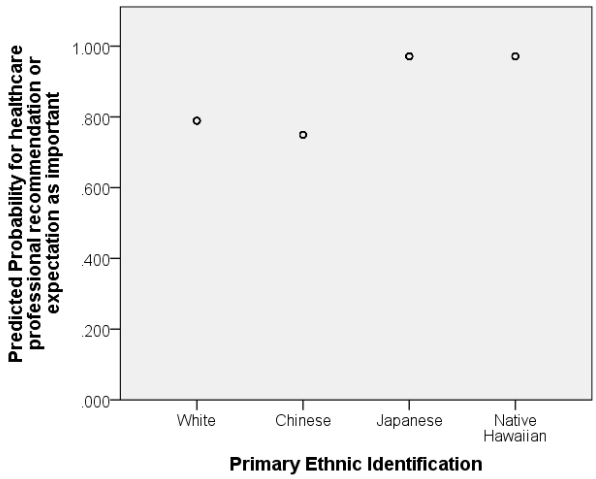
Assumption validity:
The largest standard deviation was far greater than two times the smallest. Interpret results with caution.

Ethnicity	Standard Deviation
Euro-American	0.0079
Chinese	0.0930
Japanese	0.0880
Native Hawaiian	0.0850



Response variable:
Decision-making factor: Financial resources and cost of healthcare

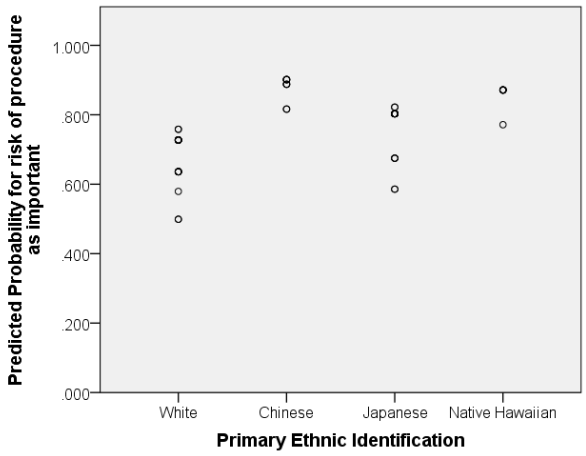
Ethnicity	Standard Deviation
Euro-American	0.0487
Chinese	0.0841
Japanese	0.0720
Native Hawaiian	0.0705



Response variable:
Decision-making factor: Healthcare professional recommendation or expectation

Assumption validity:
The largest standard deviation was far greater than two times the smallest. Interpret results with caution.

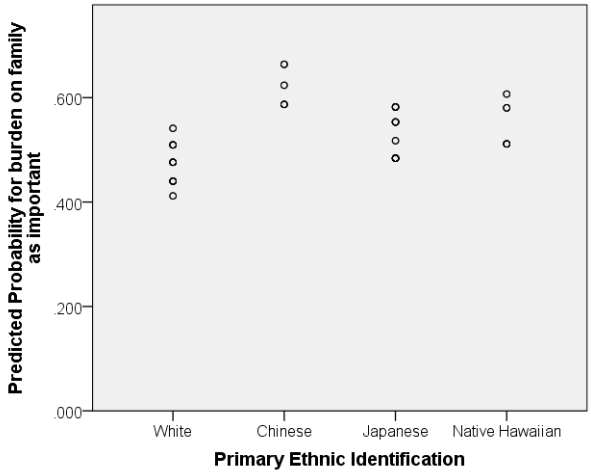
Ethnicity	Standard Deviation
Euro-American	3.3342×10^{-11}
Chinese	3.6627×10^{-11}
Japanese	0
Native Hawaiian	0



Response variable:
Decision-making factor: Risk of procedure

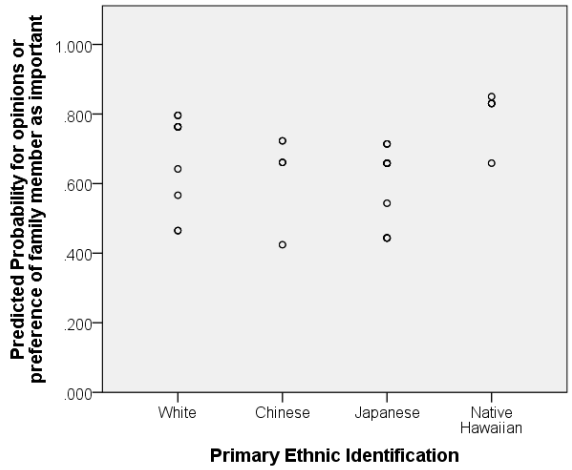
Assumption validity:
The largest standard deviation was slightly greater than two times the smallest

Ethnicity	Standard Deviation
Euro-American	0.0790
Chinese	0.0355
Japanese	0.0720
Native Hawaiian	0.0354



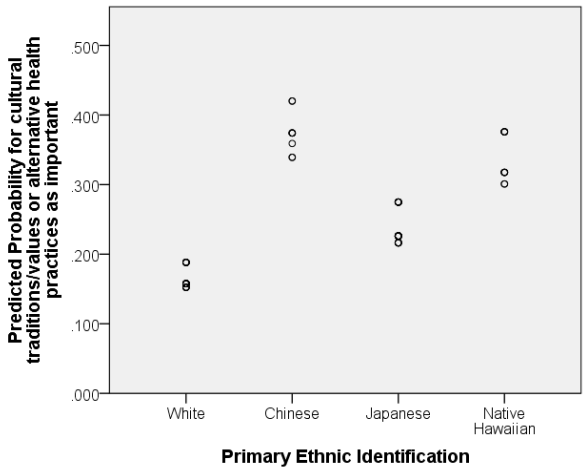
Response variable:
Decision-making factor: Burden on family

Ethnicity	Standard Deviation
Euro-American	0.0388
Chinese	0.0356
Japanese	0.0406
Native Hawaiian	0.0431



Response variable:
Decision-making factor: Opinions and preference of family members

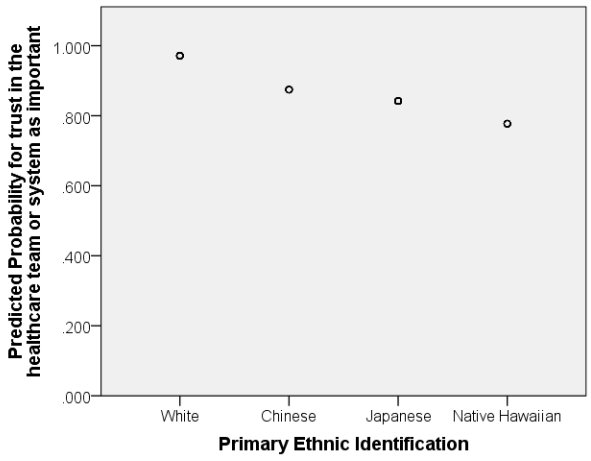
Ethnicity	Standard Deviation
Euro-American	0.1284
Chinese	0.1196
Japanese	0.1116
Native Hawaiian	0.0716



Response variable:
Decision-making factor: Cultural traditions/values or alternative healing practices

Assumption validity:
The largest standard deviation was slightly greater than two times the smallest

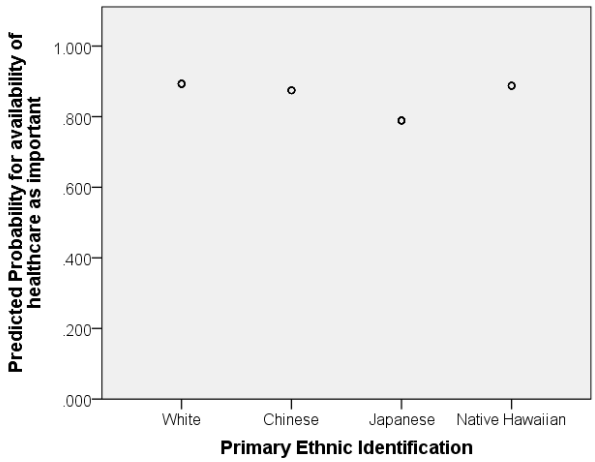
Ethnicity	Standard Deviation
Euro-American	0.0152
Chinese	0.0293
Japanese	0.0243
Native Hawaiian	0.0336



Response variable:
Decision-making factor: Trust in the healthcare team or system

Assumption validity:
The largest standard deviation was far greater than two times the smallest. Interpret results with caution.

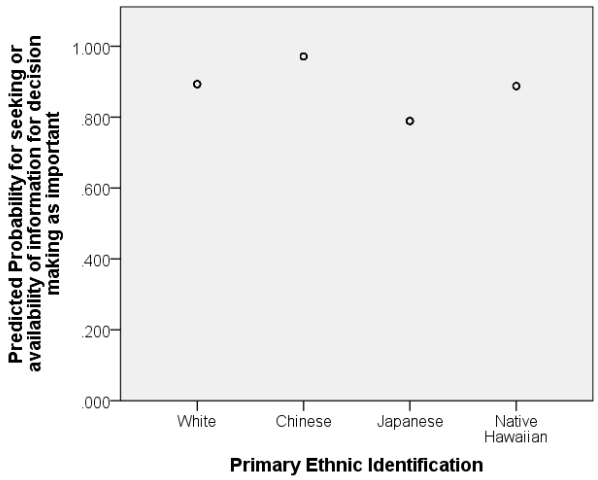
Ethnicity	Standard Deviation
Euro-American	0
Chinese	1.0635×10^{-13}
Japanese	1.1795×10^{-13}
Native Hawaiian	1.9089×10^{-13}



Response variable:
Decision-making factor: Availability of healthcare

Assumption validity:
The largest standard deviation was slightly greater than two times the smallest.

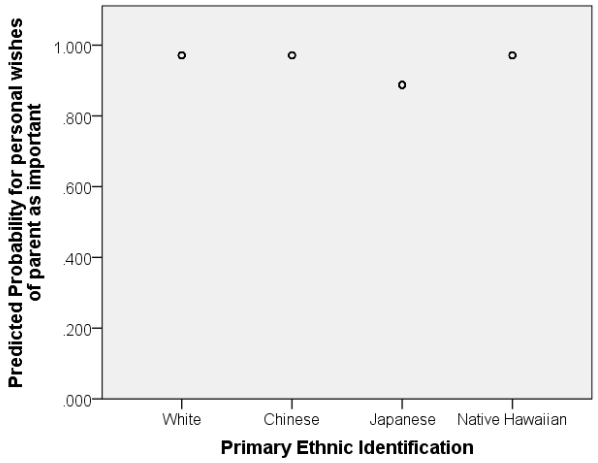
Ethnicity	Standard Deviation
Euro-American	1.4269×10^{-11}
Chinese	1.8489×10^{-11}
Japanese	2.7962×10^{-11}
Native Hawaiian	1.3773×10^{-11}



Response variable:
Decision-making factor: Seeking or availability of information for decision-making

Assumption validity:
The largest standard deviation was far greater than two times the smallest. Interpret results with caution.

Ethnicity	Standard Deviation
Euro-American	2.1276×10^{-12}
Chinese	0
Japanese	4.2584×10^{-12}
Native Hawaiian	2.0537×10^{-12}



Response variable:
Decision-making factor: personal wishes of parent

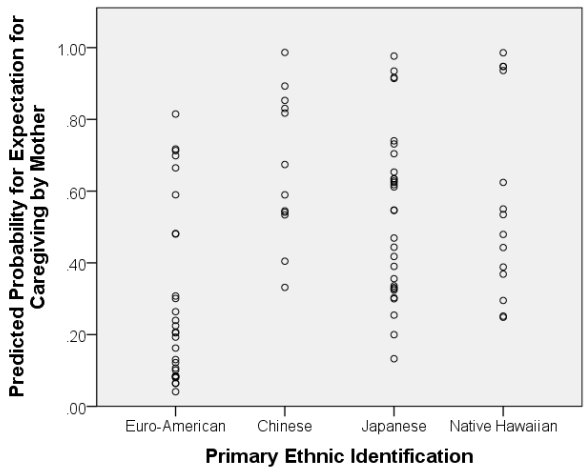
Assumption validity:
The largest standard deviation was far greater than two times the smallest. Interpret results with caution.

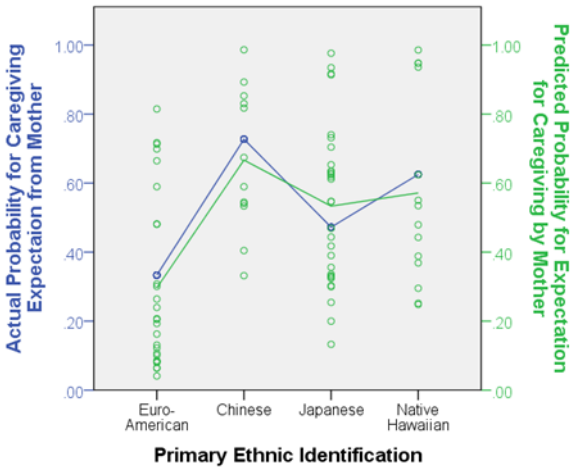
Ethnicity	Standard Deviation
Euro-American	0
Chinese	0
Japanese	8.0599×10^{-9}
Native Hawaiian	0

The assumptions for the adjusted generalized linear mixed models are (1) independence, (2) equal variance for the random effect, and (3) proper fit. The fit of the model was assessed by plotting the actual and predicted probabilities for each observation on a scatter plot and seeing if their respective averages was similar for each ethnic group. Also, the chi-square divided by the degrees of freedom should be approximately equal to or less than one. In addition to assessing the assumptions, high leverage observations were identified by plotting the residuals against the

predicted probabilities for each observation. The equal variance and proper fit assumption was valid and there were no influential observations, unless otherwise stated.

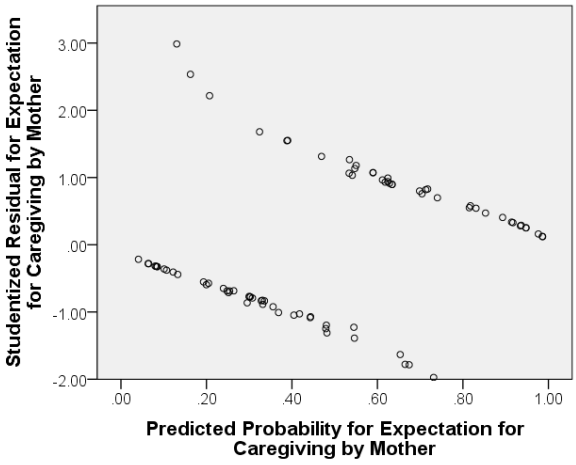
Response Variable: Expectation to be a caregiver for mother



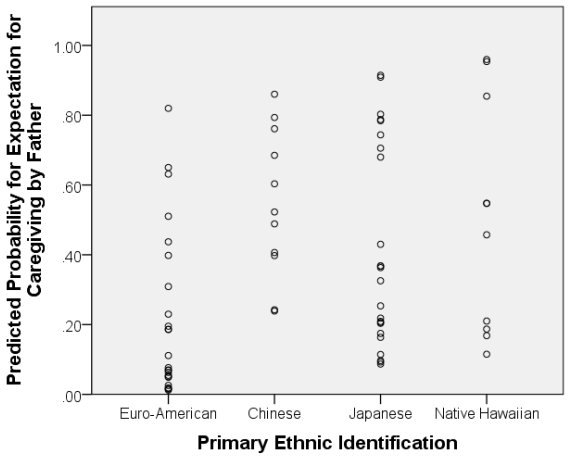


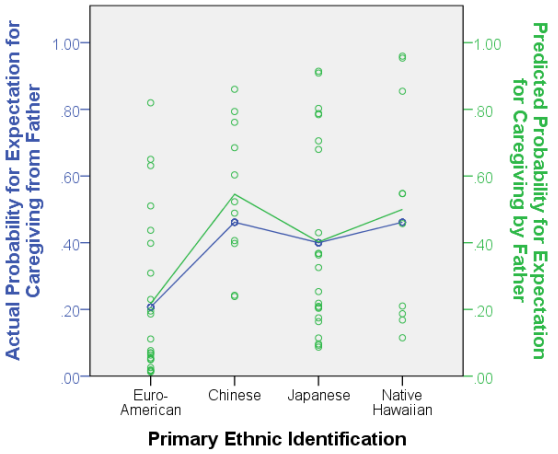
Ethnicity	Standard Deviation
Euro-American	0.244
Chinese	0.207
Japanese	0.229
Native Hawaiian	0.274

Assumption Validity: The χ^2/df was 0.96.

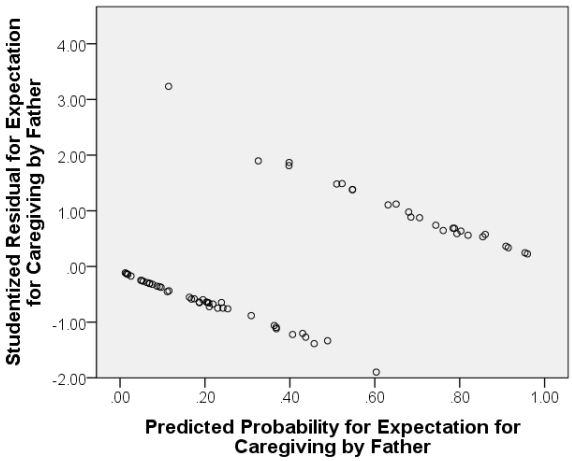


Response Variable: Expectation to be a caregiver for father



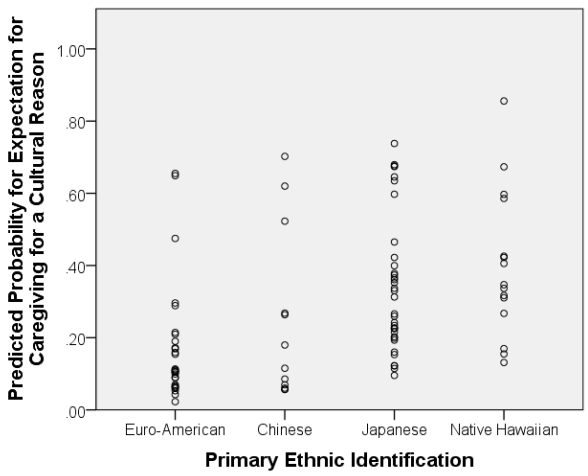


Ethnicity	Standard Deviation
Euro-American	0.236
Chinese	0.215
Japanese	0.289
Native Hawaiian	0.332



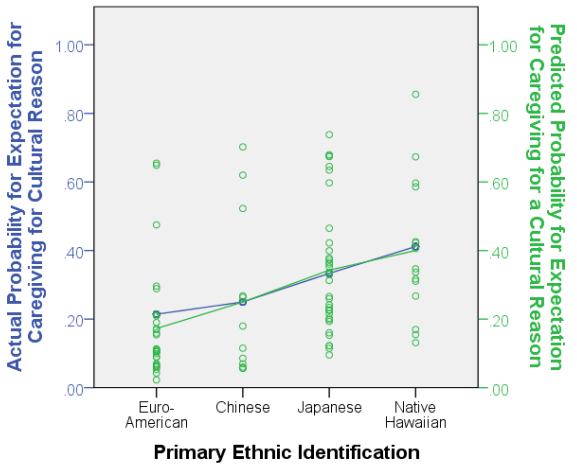
Assumption Validity: The χ^2/df was 0.79. There was one value on the top left hand corner of the leverage plot that had a very low probability but was predicted to have an expectation to be a caregiver for father.

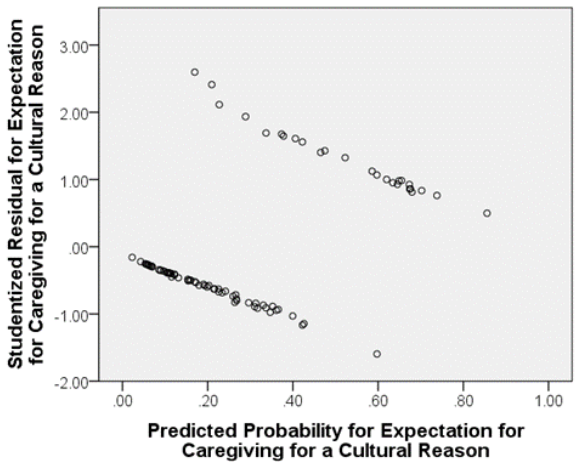
Response Variable: Expectation for caregiving for a cultural reason



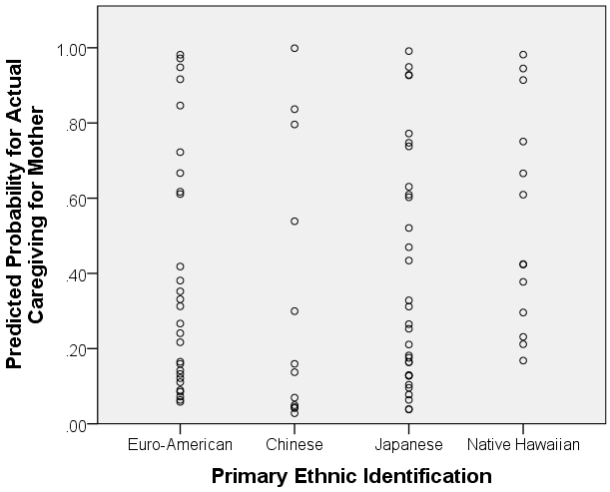
Ethnicity	Standard Deviation
Euro-American	0.163
Chinese	0.235
Japanese	0.187
Native Hawaiian	0.204

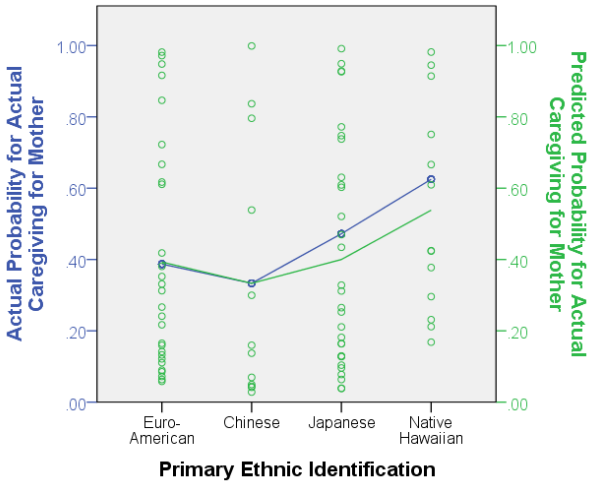
Assumption Validity: The χ^2/df was 0.80. There was one point in the bottom right of the graph that had a large predicted probability but was predicted to have no expectation for caregiving for a cultural reason.



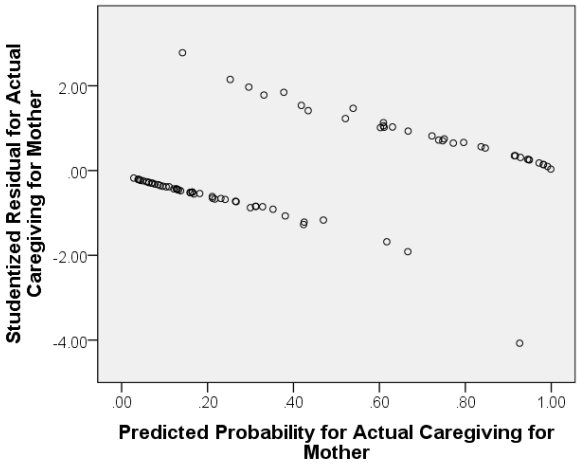


Response Variable: Actual caregiving/decision-making responsibilities for mother



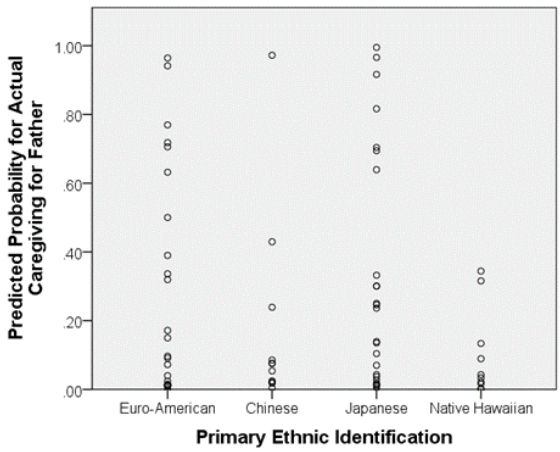


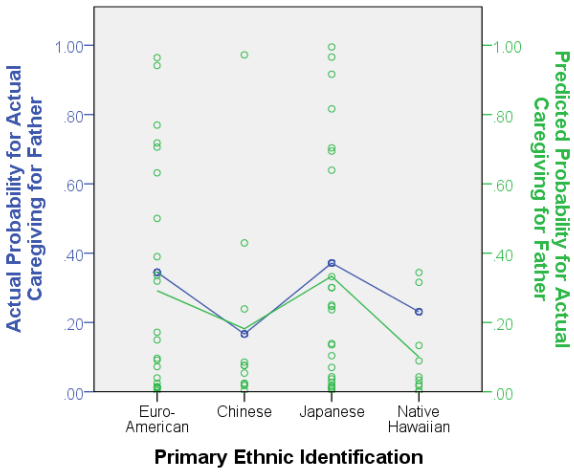
Ethnicity	Standard Deviation
Euro-American	0.318
Chinese	0.361
Japanese	0.312
Native Hawaiian	0.291



Assumption Validity: The χ^2/df was 0.87. There was one point on the bottom right corner of the leverage plot that had a large predicted probability but was predicted to not have actual caregiving responsibilities for the mother.

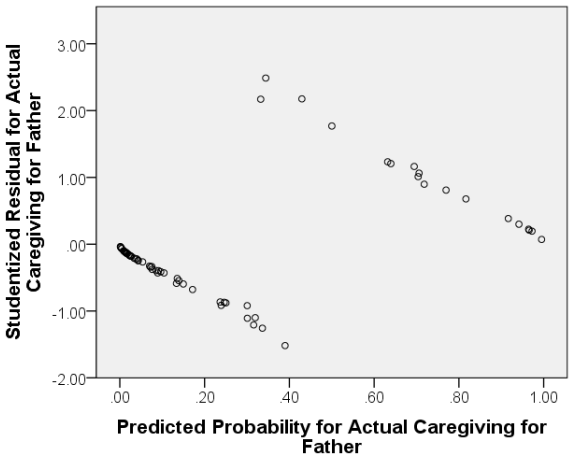
Response Variable: Actual caregiving/decision-making responsibilities for father



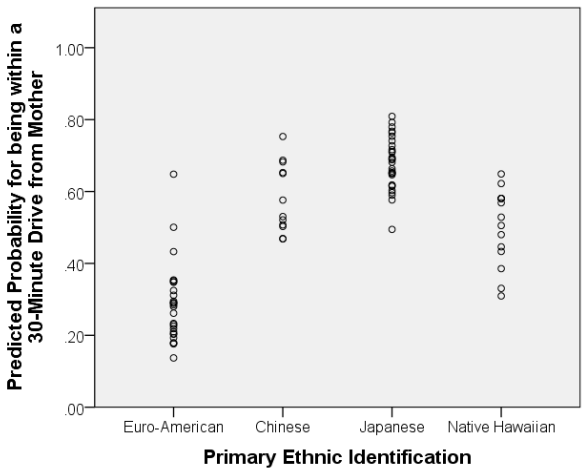


Ethnicity	Standard Deviation
Euro-American	0.328
Chinese	0.291
Japanese	0.340
Native Hawaiian	0.128

Assumption Validity: The χ^2/df was 0.46.

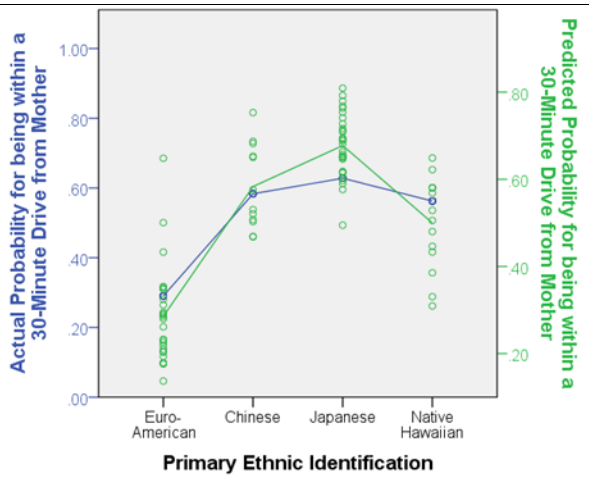


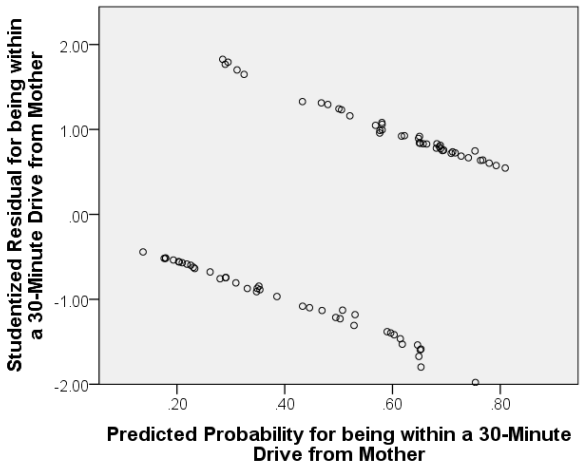
Response Variable: Geographic proximity to mother



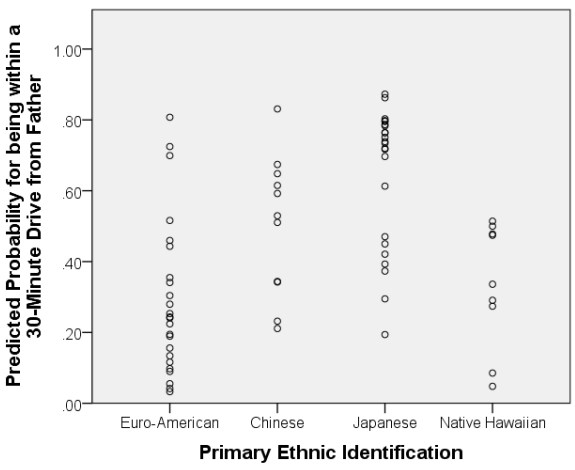
Ethnicity	Standard Deviation
Euro-American	0.108
Chinese	0.097
Japanese	0.071
Native Hawaiian	0.011

Assumption Validity: The largest standard deviation is much greater than two times the smallest. The χ^2/df was 1.05.



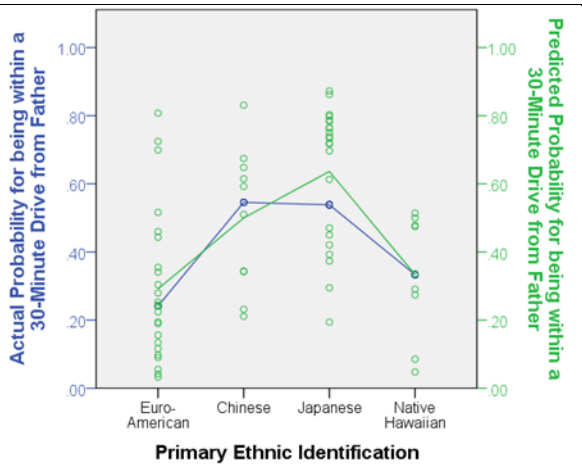


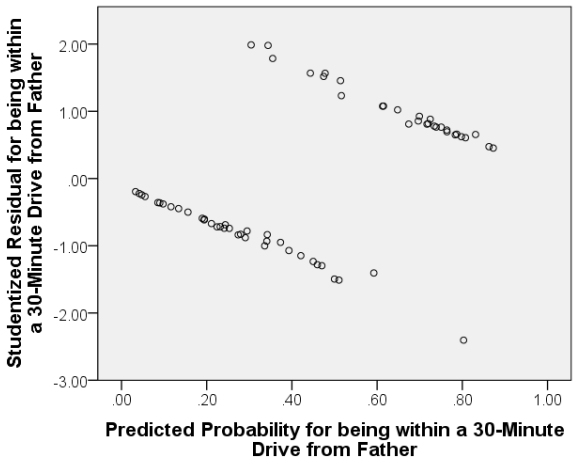
Response Variable: Geographic proximity to father



Ethnicity	Standard Deviation
Euro-American	0.218
Chinese	0.197
Japanese	0.198
Native Hawaiian	0.177

Assumption Validity: The χ^2/df was 0.90. In the bottom right corner, there was one observation with a large predicted probability but was predicted to not be within a 30-minute drive from the father.

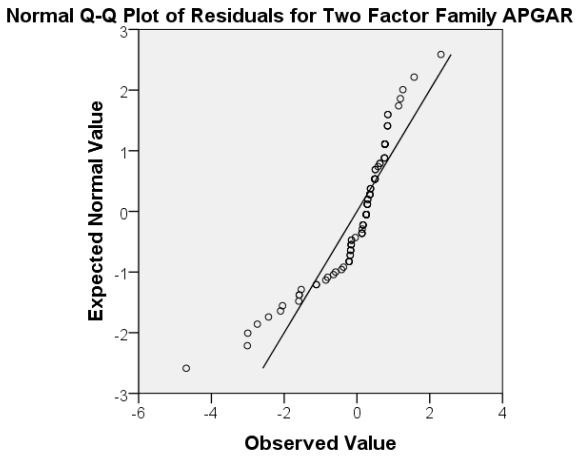


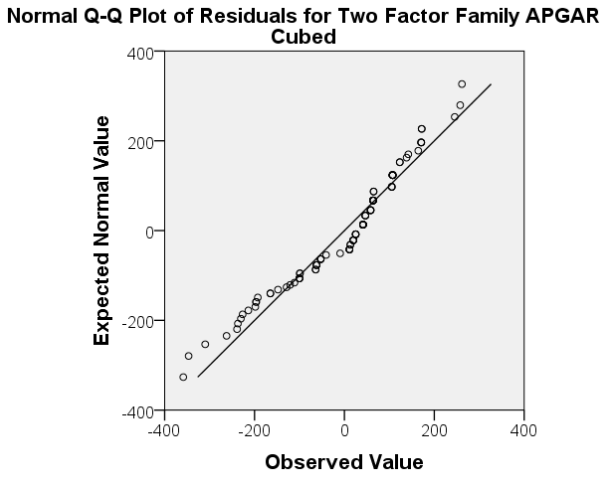


The assumptions for the unadjusted general linear models are: (1) independent observations, (2) normal error residuals, (3) equal variances for error residuals, (4) normal random effects, and (5) equal variances for random effects. Normal Q-Q plots were used to assess the normality of the residuals. Residuals were plotted against primary ethnic identification to visually assess the equal variance assumption. Also, the standard deviation of the residuals for each ethno-racial group was calculated and compared. The equal variance assumption was considered to be valid if the largest standard deviation was no greater than two

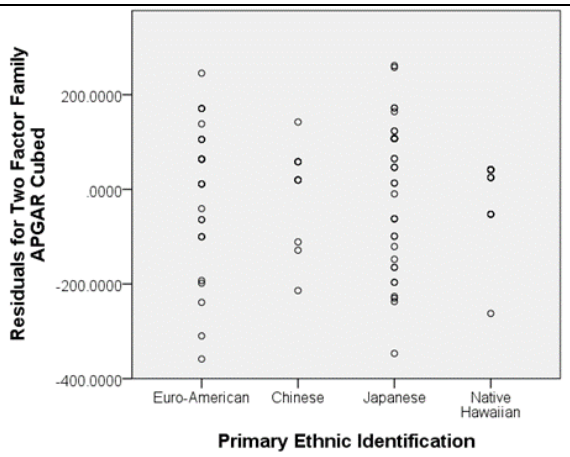
times the smallest standard deviation. The predicted probability for each observation was also calculated to assess the equal variance assumption for the random effects, in the same manner as described previously.

Response Variable: Family APGAR

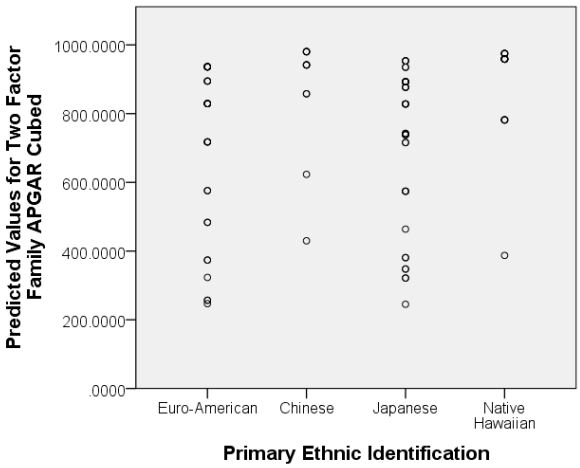




Assumption Validity: The residuals from the Family APGAR model had a long-right tail. To make the residuals more normal, the Family APGAR scores were cubed. Although there still is a slight skew, there was a large number of observations and the normal residuals assumption should be valid by the central limit theorem.

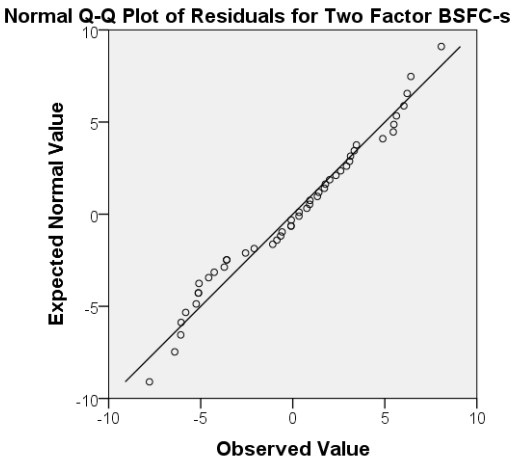


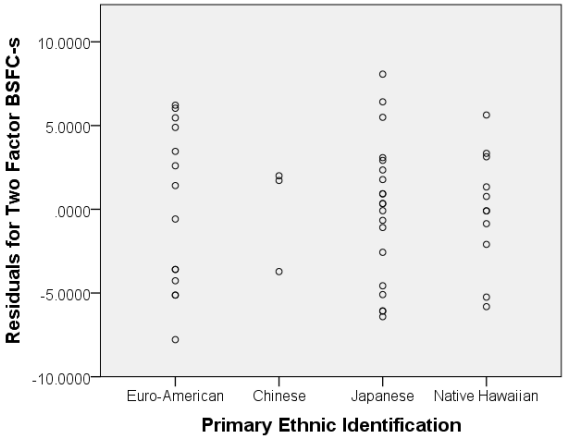
Ethnicity	Standard Deviation
Euro-American	145.06
Chinese	100.01
Japanese	150.55
Native Hawaiian	75.86

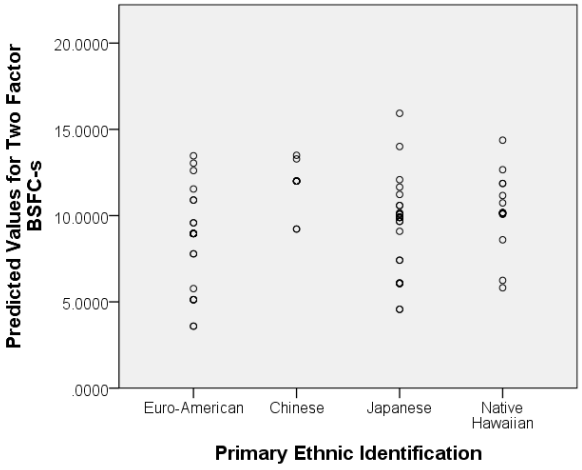


Ethnicity	Standard Deviation
Euro-American	240.59
Chinese	171.68
Japanese	220.37
Native Hawaiian	147.70

Response Variable: BSFC-s scores







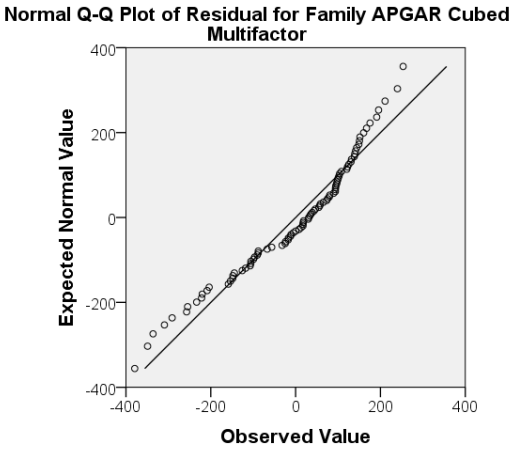
Ethnicity	Standard Deviation
Euro-American	2.52
Chinese	1.30
Japanese	2.31
Native Hawaiian	1.99

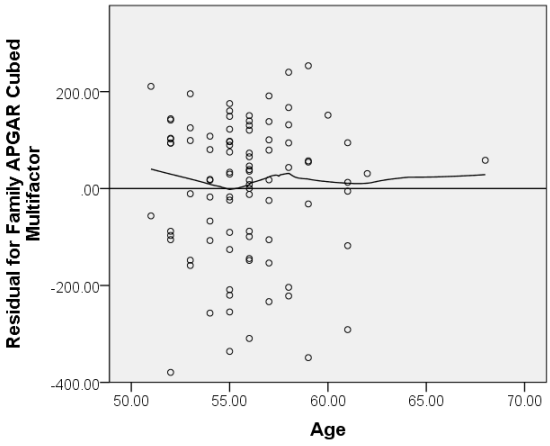
Ethnicity	Standard Deviation
Euro-American	4.86
Chinese	3.22
Japanese	4.20
Native Hawaiian	3.49

Assumption Validity: Although there was a slight skew, there was a large number of observations and the normal residuals assumption should be valid by the central limit theorem.

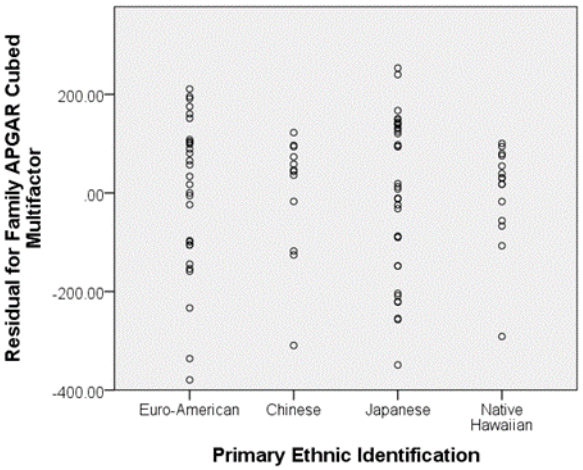
The assumptions of the adjusted general linear model are the same as the unadjusted general linear model with the addition that quantitative explanatory and response variables must have a linear relationship and influential observations must be evaluated. Linearity was assessed by plotting the residuals against age (the only quantitative predictor variable). An observation with a DFFIT value greater in magnitude than 1 was considered to have high influence.

Response Variable: Cubed Family APGAR scores

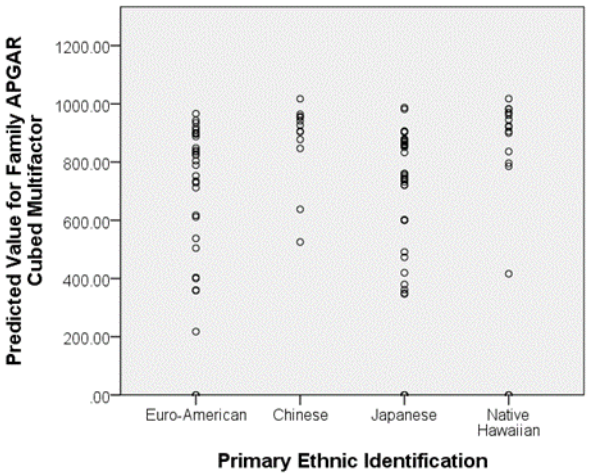




Assumption Validity: Although there was a slight skew, there was a large number of observations and the normal residuals assumption should be valid by the central limit theorem. The largest standard deviation for the predicted probabilities was slightly greater than two times the smallest standard deviation. There was only one observation that had a DFFIT value with magnitude greater than 1 (DFFIT=-1.43). It was a participant with the age of 52 and the residual -379.35 (see diagram above).

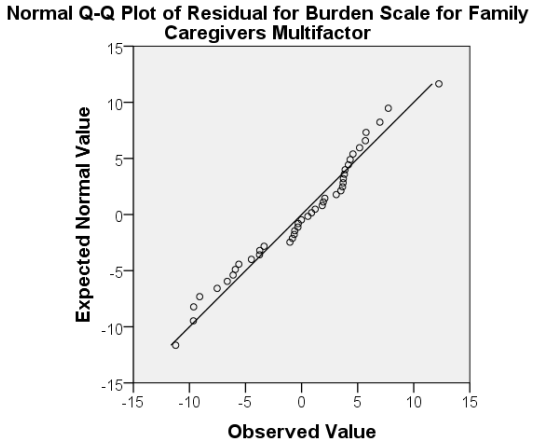


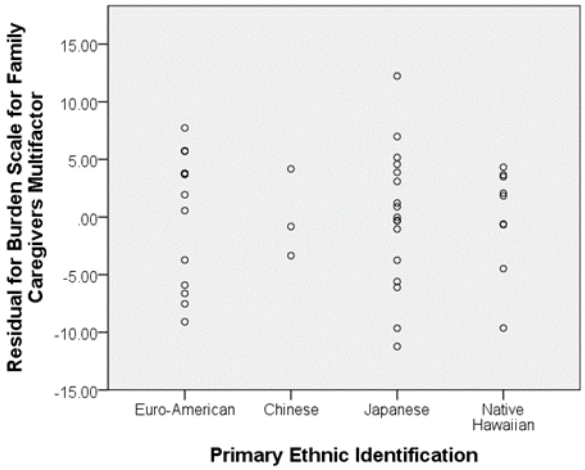
Ethnicity	Standard Deviation
Euro-American	156.76
Chinese	125.39
Japanese	160.08
Native Hawaiian	100.79

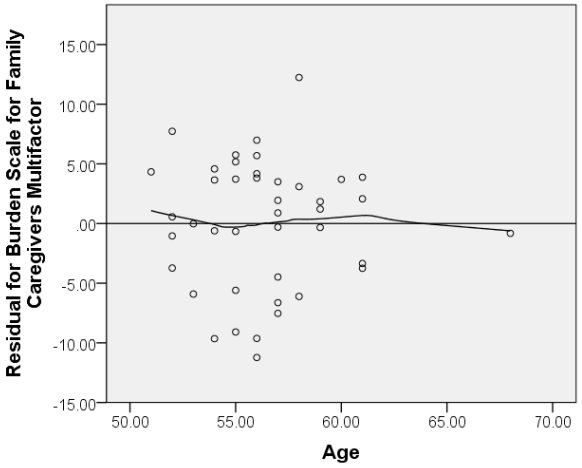


Ethnicity	Standard Deviation
Euro-American	272.60
Chinese	144.28
Japanese	270.23
Native Hawaiian	356.63

Response Variables: BSFC-s scores

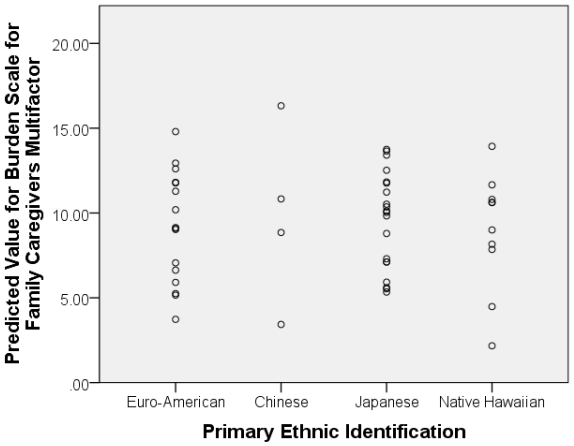






Ethnicity	Standard Deviation
Euro-American	5.80
Chinese	3.83
Japanese	6.00
Native Hawaiian	4.55

Assumption Validity: The normal Q-Q plot was relatively linear. There were four observations with absolute values of DFFITS greater than 1. These DFFITS were not major deviations away from the rule and the points were not very far away from the general aggregate of observations.



Ethnicity	Standard Deviation
Euro-American	3.26
Chinese	5.32
Japanese	2.84
Native Hawaiian	3.48